



## Continuing healthcare for children and young people

This factsheet is designed to explain what NHS continuing care is and how to apply for it if you think you or a family member under the age of 18 might be eligible. It also covers the assessment process and what to do if you disagree with the decision reached.



### What is NHS continuing care?

Continuing care is a package of care funded by the NHS for a child or young person who has complex, ongoing healthcare needs as a result of an accident, disability or illness.

If eligible, the NHS will fund an appropriate package of care to meet the health and personal care needs of the individual, whether at home or in a residential care setting.

It is accepted that a wide range of agencies are likely to be involved in the case of a child with continuing care needs, predominantly health, social care and education. It is not unusual for a continuing care package to include a range of services commissioned by the Clinical Commissioning Group (CCG), Local Authority or even other agencies. Where this is necessary, the CCG should take responsibility for leading the process.

### The National Framework

The National Framework for Children and Young People's Continuing Care 2016 sets out the principles and processes for establishing eligibility for NHS continuing care for applicants under the age of 18.

The Framework provides guidance to be followed by those involved in the assessment process. It sets out a national assessment process and provides an assessment toolkit to support decision making; including a pre-

assessment checklist and Decision Support Tool. There is separate guidance for adults.

One of the core values of the Framework is that the process should focus on the child or young person, initially in the context of their family, and later to support them in the transition to adulthood. The Framework aims to place the individual at the heart of the assessment process. It ensures an individual's views are taken into account and that their preferences regarding having identified needs met are properly considered.

### The process

The CCG is responsible for leading the process and determining eligibility. Children and young people can be referred to the CCG for assessment by any health or social care professional involved in the person's care or by the family directly.

There are three stages in the continuing care process:

1. The assessment – including pre-assessment if appropriate
2. Decision making
3. Arrangement of provision.

### The assessment

The Framework suggests that the pre-assessment checklist ought to be used flexibly to determine whether

a full assessment is required. Pre-assessments may require input from professionals and any decisions must be made quickly, within 1-2 days, and with robust, fully documented reasoning.

There are 10 distinct care domains or areas of need. These are sub-divided into different bands for scoring purposes (priority, severe, high, moderate, low and no needs). The levels reflect the nature, intensity, complexity and unpredictability of the need.

The care domains are as follows:

- Breathing
- Eating and drinking
- Mobility
- Continence or elimination
- Skin and tissue viability
- Communication
- Drug therapies and medication
- Psychological and emotional needs (beyond what is typically expected from a child or young person of their age)
- Seizures
- Challenging behaviour

All assessments have to be evidence based. It is important to remember that needs should not be marginalised just because they are successfully managed - well-managed needs are still needs.

### Decision making

Following completion of the assessment, the assessor should produce a recommendation for presentation to a decision-making forum. The panel should be independent from those involved in the assessment and include key CCG and local authority professionals and at least one clinician.

The decision should ideally be made within six weeks of the commencement of the assessment (ie following the pre-assessment if appropriate). The decision should be communicated verbally to the family within five working days to be followed with a written explanation for the decision.

### Eligibility

To be eligible for NHS continuing care it has to be shown, as a result of the assessment, that the care required by the child or young person goes beyond that

which can be provided by existing services available to all, or by specialist services alone. Where additional health support is required, the additional package of support is known as continuing care.

A clear recommendation of eligibility for NHS continuing care would be expected where the child or young person scored:

- three “high” levels of need;
- one “severe” level of need; or
- one “priority” level of need.

However, this is a guideline and should not be used restrictively.

### Arrangement of provision

The National Framework states that after the decision-making phase, where a child or young person qualifies for NHS continuing care, the CCG is responsible for putting the plan into action and making sure that an agreed package of care is put into place as soon as possible.

The package of care must be shaped by the child or young person’s needs and the process of assessment will inform the development of the package. Preferences of the child or young person should be considered together with a variety of other factors.

### Urgent Consideration

Where urgent consideration of eligibility is required, for example where the applicant has a rapidly deteriorating condition, CCGs should take immediate action to meet the needs of the child or young person and then, where appropriate, a continuing care assessment should take place.

### Challenging a decision

Decisions on eligibility can be challenged in writing to the CCG requesting a review, in accordance with the local complaints procedure.

### Review

Children or young people entitled to NHS Continuing Care ought to have their needs reviewed on an annual basis to ensure that they are continuing to receive appropriate support.

PACE is a ground-breaking children’s charity that transforms the lives of children and young people with motor disorders, such as cerebral palsy. If you or a family member require advice and support, you can discuss your circumstances by contacting us on 01296 392 739 or email [info@thepacecentre.org](mailto:info@thepacecentre.org).

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