

Children's Continuing Care: Information for Referrers

What is Children's Continuing Care?

Some children and young people (up to the age of 18) may have very complex health needs that require additional health support which is not routinely available. This additional health support is known as 'Children's Continuing Care'.

A Continuing Care package may be required when a child or young person has needs arising from a disability, accident or illness that cannot be met by existing universal or specialist services alone. Continuing care does not cover children and young people with care needs that may be met appropriately through existing universal (services available to all such as GP, Health Visiting and Emergency Department services) or specialist health services (such as Lifetime, Jessie May, Charlton Farm, CAMHS LD).

The Children's Continuing Care process is guided by the National Framework for Children and Young People's Continuing care (Department of Health, 2016) [Children and young people's continuing care national framework - GOV.UK](#)

Responsible team

The Children's Complex Care Team at the ICB (NHS Integrated Care Board) in your local area are responsible for assessing children and young people to see if they are eligible for Continuing Care. The team are paediatric senior nurses by background and have Case Management roles. The team is managed by the Lead for Children and Young People's Continuing Care.

The team email is bnssg.cc.childrens@nhs.net

Each BNSSG area has a lead nurse, please contact the team to find out who the area lead is for your local authority area.

Consultation

Please consider a consultation with the dedicated CCC Case Manager in your area if you are unsure whether the child or young person should be referred. We will arrange a 15–30-minute consultation via Microsoft Teams. Please contact the team by emailing bnssg.cc.childrens@nhs.net or calling 0117 900 2626 option 3 to arrange a consultation.

Referral

The referral form asks for the following:

- Information on 10 specific areas of need. These are Breathing, Eating and Drinking, Mobility, Continence, Skin and Tissue Viability, Drug Therapies and Medication, Psychological and Emotional Needs, Seizures and Challenging Behaviour.

- Additional supporting information - this must be up-to-date information (within a year) and can include a copy of the child's EHCP, recent clinic letters, care plans, risk assessments etc.
- Evidence that universal and specialist services are involved or have been exhausted.
- Details of the current unmet health need.
- Details of any risks that we should know about before entering the child's home.
- For the referrer to complete CCC consent form with the parent/carer or young person if over 16 and able to do so. Please ensure that the consent form is signed and dated by the P/CYP and submit with the referral.

Once you have fully completed the referral, please submit it via bnssg.cc.childrens@nhs.net

Triage

Referrals are triaged by 2 nurses from the Children's Complex Care team; this will determine whether a full assessment is required based on the information provided. You may be asked to provide additional information for the referral to be fully triaged. You will be informed of the decision to assess or not within 5 working days.

Assessment

The assessment is completed with the child and their family at the family home. Sometimes we will meet the child at school or in a respite care setting too. The referrer is invited to join the assessment. The assessment includes:

- the preferences of the child or young person and their family;
- holistic assessment of the child or young person and their family;
- reports and risk assessments from the multidisciplinary team.

The information is collated into a Decision Support Tool (DST) document ready for consideration by the ICB.

Decision

To be eligible for Children's Continuing Care funding, a child or young person must have high needs in 3 out of the 10 care categories or domains. Some of the categories have levels of needs that are described as *severe* or *priority*, in which case only one of these categories indicates eligibility.

Individual cases are discussed in a multi-professional meeting where decisions are based on the nature of the child's needs rather than the diagnosis they have or the care or service that is or is not available. Consideration is also given to the intensity and frequency of health interventions as well as the complexity and unpredictability of the child or young person's needs. A recommendation is then made as to whether the child or young person should or should not be eligible for NHS Children's Continuing Care funding. The Case Manager then meets with the Lead for Children's Continuing Care where the final decision is reached.

Notification

The Case Manager will inform the parents/carer usually by telephone and followed up with the formal decision in writing. The referrer is also informed. We aim to have a decision 6 weeks after receiving the referral.

Provision

If a child is eligible for NHS Children's Continuing Care, it is likely that a range of organisations will be involved, such as the local authority children's services and education. These different agencies may contribute to a child's package of care if they are found to have continuing care needs. A package of care is discussed with the child or young person (where appropriate) and their family and the best way of managing it is agreed. This may include offering a child or young person a Personal Health Budget which can be arranged as either as a notional budget, a third-party arrangement or a direct payment.

The Case Manager will be responsible for overseeing delivery of the support package and will provide ongoing monitoring from a commissioning and quality assurance perspective.

Review

The child or young person's continuing care needs will be reviewed three months after the package of care has commenced. The child/young person's continuing care needs will thereafter be reviewed annually or if their needs have changed.

For further information:

- NHS England Children's Continuing Care Training available on the E-learning for healthcare platform <https://portal.e-lfh.org.uk/Component/Details/847262>
- NHS England also run regular regional training for Children's Continuing Care: <https://www.events.england.nhs.uk/search?q=CYPCC>
- ICB Children's Continuing Care online training sessions scheduled quarterly. Email bnssg.cc.childrens@nhs.net to find out the dates of upcoming sessions.

Relevant documents:

- [Children and Young People's Continuing Care - Referral form](#)