## North East Lincolnshire Children’s Complex Health Team

# Guidance for Requesting a Children’s Continuing Care Assessment

### What is Children and Young People’s Continuing Care?

A specialist package of care and support may be required when a child or young person, up to the age of 18 years, has complex health needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone. This specialist package is called Continuing Care.

Further information regarding the National Framework for Children and Young People’s Continuing Care can be found on the government website: [Children and young people’s continuing care national framework - GOV.UK (www.gov.uk)](https://www.gov.uk/government/publications/children-and-young-peoples-continuing-care-national-framework)

### What to consider before making a referral

Continuing care assessments enable a holistic understanding of the needs of the child/young person and their family. Their views and preferences regarding what they feel they need and how they would like care to be delivered are central to the assessment and development of the package of care.

The child/young person and their family MUST be involved at every stage of the process. **It is therefore essential that you have discussed with the family the identified unmet health needs and what they hope to achieve through continuing care. This must be communicated clearly in your referral.**

***Unless there is a good reason for this not to happen, continuing care should be part of a wider package of care, agreed and delivered in collaboration between health, education, and social care (Department of Health, 2016).*** Therefore**,** before making a referral for a continuing care assessment, it is important that you have considered involvement of all relevant universal and specialist services. It would be unusual for a referral to be considered without the child or young person having input from multiple services such as: Children’s Community Nursing Team; Young Minds Matter; Andy’s Hospice; Paediatricians; NELC Children’s Services; NELC SEND and Inclusion teams.

*It is recommended that you contact the Children’s Complex Health Team to discuss the case prior to referral:* [*cchc@nelincs.gov.uk*](mailto:cchc@nelincs.gov.uk)

### Making a referral

Consent:

To make a referral please ensure that you have discussed this with the child/young person and/or the person(s) with parental responsibility and completed the consent form. A ‘Children and Young People’s Continuing Care: Guide for Young People and Parents’ is available on request from the Complex Health Team to support this discussion.

For young people aged 16+, evidence must be provided that the Mental Capacity Act has been considered.

Completing the pre assessment checklist:

Please complete the ‘Children and Young People’s Continuing Care Pre-Assessment Checklist’. This can be requested from the Children’s Complex Health Team.

When completing the checklist please complete all boxes to the best of your knowledge. You will need to speak with other professionals involved in the child or young person’s care to complete this. If a domain is not completed, we will assume during the screening process that there are no additional needs in this area.

When completing the care domains please:

* provide a brief explanation of the health need and rational for the score, taking into consideration the child/young person’s age and development.
* refer to the ‘what to consider’ section below for ideas on types of health needs
* attach any evidence to support each of the areas of need you have commented on. Examples of evidence may include care plans, clinical letters, 24 hour diaries, incident reports, professional reports, risk assessments, LAC reports, EHC plan, etc.
* clearly explain what the **unmet** health needs are and the child, young person’s and/or family’s preferences around how they would like these to be met.

Great Ormond Street Hospital provide a ‘health dictionary’ which may help you when completing the checklist if you are unsure on the medical terms:

<https://www.gosh.nhs.uk/conditions-and-treatments/health-dictionary/>

What to consider:

A child or young person may be eligible for continuing care if their needs are assessed as ‘high’ in at least 3 domains or ‘severe’ or ‘priority’ in at least one domain. However, this is only a guide and full assessment involves consideration of a range of information.

* Breathing

Does the child need inhalers/nebuliser? Do they need antibiotics all the time to prevent infections? Do they require chest physio? Do they require oxygen? Are they ventilated? If so for how many hours per day? Does the child/young person need suctioning, if so approximately how many times per day and/or night? Is it oral or nasopharyngeal? Does the child have frequent chest infections? How are these needs being met and are there any unmet needs?

Examples:

High – child with tracheostomy, nighttime ventilation can be disconnected without clinical harm. Effective suction beyond back of throat

Severe –unstable tracheostomy requiring frequent changes due to frequent blockage, nighttime ventilation would survive disconnection but likely to be unwell and require hospitalisation.

Priority – 24/7 ventilation, disconnection would be fatal. Highly unstable tracheostomy requiring daily changes or difficult to change. Congenital Central Hypoventilation Syndrome (CCHS)

* Eating and Drinking:

Does the child eat orally? Do they have issues with feeding? Do they have reflux or vomit frequently? How long does it take somebody to feed them? Have they issues with their swallow? If they have a gastrostomy, PEG etc. does it block frequently? Is it frequently infected? Does the child/young person pull it out? Does the child/young person struggle to absorb their food? Do they need a specialist diet plan? Are they under/overweight? Do they have any food allergies/intolerances? How are their needs being addressed and have these measures been effective? If not reasons why. Which medical professionals are monitoring this condition? How often are they reviewed by a medical professional?

Examples:

High – faltering growth despite specialised feeding plan and professionals indicating concern. Complex feeding routine by SaLT but still at risk of choking or aspiration. Severe undernourishment due to anxiety which prevents intake i.e. anorexia. Complex Naso Gastric feeding (does not include Gastrostomy or Jejunostomy tube). *Straightforward Gastrostomy or Jejunostomy tubes are moderate.*

Severe – Total Parenteral Nutrition (TPN) – feeding via intravenous route

* Mobility:

Are they able to take any weight through their legs? Do they have any functional movement of their hands? Do they have issues with bone density, skin or jerky movements that affect the way carers move them? Are parents/carers disturbed in the night to turn them or reposition them? Do they require any specialist equipment? What health intervention has been advised? Is this helping, if not reasons why. Do they have a physio program, how long does this take? Which medical professionals are monitoring this condition? How often are they reviewed by a medical professional?

Examples:

High – managed by mechanical moving and handling, unable to mobilise or assist in moving position. High risk of fracture due to bone density.

Severe – total paralysis, movement causing blocking of airway, some severe skin conditions.

* Continence/Elimination:

Is the child continent? Do they have urine or faecal accidents? Do they smear? Do they have frequent urine infections? Do they need stoma’s/catheters or medical intervention to control their elimination needs? Are they constipated? Advice and treatment so far? Has this helped? If not, please give reasons. Which medical professionals are monitoring this condition? How often are they reviewed by a medical professional?

Examples:

High – Severe on-going diarrhoea, maybe caused by a long-term infection, problematic urinary issues such as a leaking urostomy. Haemodialysis in hospital, intermittent catheterisation.

Severe – hemodialysis or peritoneal dialysis at home

* Skin and Tissue Viability:

Does the child have a diagnosed skin condition? What treatment medical advice has been given? Has this helped? Reason why it has not helped. Does the child have problems due to excessive dribbling, frequent loose stools, and gastrostomy? How often does the condition need clinical assessment? Does the child/young person need specialist dressings? How long do these take to do? Does the carer need specialist advice and training to do the dressings? Do they need any special medication/creams to prevent infection, skin breakdown? Which medical professionals are monitoring this condition? How often are they reviewed by a medical professional?

Examples:

High – open pressure wounds requiring daily treatment and pressure relieving equipment, complex skin condition e.g severe neurofibromatosis.

Severe – life threatening skin conditions ( e.g necrotising fasciitis or Epidermolysis bullosa EB) requiring daily and complex interventions or severe burns.

* Communication:

Are they able to express their basic needs e.g. hunger, pain. How do they do this? Do they use PECS, eye gaze, body language? Is their communication effected by their mood, tiredness etc? What support have they had so far? Is this support helping? Please give reason if support not helping. Which medical professionals are monitoring this condition? How often are they reviewed by a medical professional?

Example:

High – may be able to smile and cry but unable to communicate needs or limited access to communication systems but not reliable.

* Medication:

How is medication given, oral/rectal/needle/gastrostomy? Can the child/young person take it themselves? Is the medication hidden to ensure it is taken? Do they require medication in the night? Do they require emergency medication, how often? How often does the child/young person need to be hospitalised because medication has not been effective, if so how often? Does the carer need extra training to give medication? How often is the medication reassessed by a qualified medical practitioner?

Examples:

High – regular (at least weekly) changes to medication e.g anti convulsants . (over the phone with parents putting changes into place).

Severe – Daily medication changes, by registered nurse and doctor e.g associated with end of life pathway and pain relief (nurse visiting daily).

Priority – would need 1-1 from nurse with input from doctor.

* Psychological/Emotional Needs:

Is the child generally cheerful? Does the child have any anxiety issues? What support has been offered so far? Has this been helpful? If not please give reason. Does the child attend school/college? Do they engage with activities? Has there been a significant deterioration in the child’s engagement, social functioning and self-care? Can this deterioration be attributed to age, peer pressure, recent event or stressful situation? Which medical professionals are monitoring this condition? How often are they reviewed by a medical professional?

Examples:

Moderate – Has CAMHS involvement and is responding to interventions/treatment.

High – Being supported by CAMHS at an increased level, i.e. crisis outreach services engaged. Interventions prescribed show limited responses. Requires MHA assessment and potential admission to T4 CAMHS for assessment and treatment.

* Seizures:

Has the child been diagnosed with epilepsy? Was the seizure linked to an event e.g. temperature, fall etc. Is the child/young person’s medication needing regularly review, if so how often and by who? Is the child/young person prescribed emergency medication? How often do they need it? How often does the child/young person need hospital admission? Has the child/young person have a VNS or other surgical seizure control procedure? Does the child need care in the night due to seizure management, if so how often? Which medical professionals are monitoring this condition? How often are they reviewed by a medical professional?

Examples:

High – Tonic/Clonic seizures requiring rescue medication (such as Midazolam) on a weekly basis.

Severe – Uncontrolled daily seizures not responding to medication and requiring hospital treatment.

* Challenging Behaviour:

When thinking about this domain please consider what the cause of the challenging behaviour is. If it is more related to the CYP mental health please score in the emotional and psychological domain. This domain is generally for CYP with challenging behaviour related to their Learning Disability.

Is the child’s behaviour predictable, e.g. when they experience something new, if they have not understood events planned. Are they using it as a way to communicate? How has their behaviour been addressed? Has any health or behaviour intervention been helpful? Is a specialist health team involved or been involved? If not please give reasons. Describe the behaviour displayed. Which medical professionals are monitoring this condition? How often are they reviewed by a medical professional? **Please note the weighting of challenging behaviour is unlikely to be a High or greater if specialist health involvement is not being currently offered and a current health assessment and plan is not available.**

Examples:

High – Expect specialist CAMHS to be involved including PBS

Severe – intense multi-agency support including CAMHS, PBS and risk of exclusions from home and school and requiring alternative provision.

Priority – Presentation continues to deteriorate and immediate safety of the child or those around them are at risk, requires MHA assessment and possible admission to specialist T4 CAMHS inpatient.

**Completed referral forms and consent forms should be emailed to :** [**cchc@nelincs.gov.uk**](mailto:cchc@nelincs.gov.uk)

**Urgent ‘Fast Track’ Referrals**

In cases where a child or young person has a rapidly deteriorating condition and an expected short term life expectancy, the team will accept ‘fast track’ referrals to ensure that a package of care can be put in place quickly, without a full assessment to determine eligibility. Completion of the pre assessment checklist is not required.

The ‘fast track’ referral form MUST be completed by a health professional and sent to [cchc@nelincs.gov.uk](mailto:cchc@nelincs.gov.uk) . Please state ‘FAST TRACK – URGENT’ in the email subject line.

Fast track referrals will be responded to within 24 hours, when received during working hours (Monday-Friday 9-4pm)

### What happens next?

All referrals for continuing care are screened by two complex health nurses. We aim to provide a response within 5 working days of receipt of the referral. We will contact you if additional information is required.

If the decision is that a full continuing care assessment is not required. We will explain the rationale for this and provide recommendations regarding additional services which may be able to help, where appropriate.

If the pre assessment indicates that the child/young person is likely to meet the eligibility criteria or if there is any doubt regarding eligibility, we will proceed to a full assessment.

We aim to complete assessments within 6 weeks of the decision to undertake a full assessment, however in some cases where the needs are highly complex and several professionals are involved, or where it is not in the best interests of the child/young person due to other assessments needing to take priority, the assessment may take longer. We will keep yourself and the family updated regarding the process throughout.