NHS Newham CCG children and young people’s continuing care policy
Key Points to this Document:

1. This document set out the process for Newham’s children, young people, and their families, or carers to access and receive Continuing Care as defined in the 2016 Children’s and Young People’s Continuing Care Framework.

2. It also provides key legislation and guidance to provide an evidence base for this document.
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1. **Introduction**

This policy describes the way in which NHS Newham Clinical Commissioning Group (NCCG) makes provision for the care of children and young people who have been assessed as eligible for NHS continuing care as outlined in the National Framework (2016) to ensure that the CCG meets its statutory responsibilities and adheres to good practice guidelines.¹

The National Framework outlines the process for assessment and subsequent eligibility for continuing care. It describes the process for assessing, deciding and agreeing packages of continuing care for children and young people. A package of continuing care is required when a child or young person has needs arising from disability, accident or illness, which cannot be met appropriately through existing universal or specialist health services.

This policy also reflects the changes to the new commissioning structures in the National Health Service (NHS) resulting from the Health and Social Care Act (2012) and the new integrated approaches to commissioning children and young people’s services with special educational needs or disability (SEND) specified in the Children and Families Act (2014).²

2. **Purpose**

The purpose of this policy is to ensure that there is a consistent approach to ensure quality, equality and transparency in the assessment and agreement of eligibility for children’s continuing care. This document must be read in conjunction with the National Framework for Children and Young People’s continuing care (2016) and supporting legislation relating to the assessment of children and young people whose complex needs cannot be met through existing universal or specialist services.

This policy also supports partnership working between NCCG, North East London Commissioning Support Unit (NELCSU), London Borough of Newham (LBN), and East London NHS Foundation Trust (ELFT).

3. **Scope**

This policy covers young people up to their 18th birthday. Thereafter, the national framework for NHS continuing healthcare and NHS-funded nursing care and the supporting guidance and tools should be used. There are significant differences between children and young people’s continuing care and NHS Continuing Healthcare for adults. Although a child or young person may be in receipt of a package of continuing care, they may not be eligible for NHS continuing healthcare or NHS funded nursing care once they turn 18. As defined in NHS England ‘Who pays’ 2013, the child or young person must have a Newham GP, or did, until they became looked after, to be eligible for care.³

In delivering this process NCCG are the lead NHS organisation, as determined by the Department of Health and therefore accountable for establishing and managing governance arrangements for the children and young people’s continuing care processes. NELCSU currently leads on the continuing care panel process on behalf of NCCG. This may however, be subject to change.

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4. Statement of intent

NCCG has a legal responsibility for assessing and commissioning the reasonable healthcare requirements for its local population. The 2016 children's continuing care framework provides guidance on how the CCG should exercise responsibility for identifying, assessment and provision of continuing care as defined in section 3 of the NHS Act 2006.4

NCCG and LBN have a statutory responsibility to meet the health care, social care and educational needs of children and young people with continuing care needs which may require services commissioned by multiple organisations. It is therefore imperative that both organisations work together to provide a holistic care package adhering to the principle of securing the best outcomes for both the child/young person and their family. However, each organisation remains responsible for its own statutory duties.

NCCG is responsible for commissioning continuing care for children and young people, for overseeing effective liaison with LBN and other partners, and the management of the process. NCCG will also ensure that the model provided is equitable, and is provided by a skill mix of registered paediatric or CAMHS nurses and suitably trained and skilled carers.

5. Statutory guidance and responsibilities

Children and young people's continuing care is different from NHS continuing healthcare for adults. It is care provided in a child centred way either in the family home, or in residential care settings, including residential special schools.

Newham's Transforming Care Programme aims to improve life for people with learning disabilities and people with autism who have challenging behaviour5. Our plan is to give the right support in the right place at the right time with each child or young person. Similarly, 'Best for All'6 is Newham's five-year strategy for SEND and inclusion. Newham's Strategy has been developed with partners and stakeholders with the shared aim of improving outcomes and removing barriers to learning for children and young people with SEND aged 0-25. Local authority have responsibilities under Section 2 of the chronically sick and Disabled Persons Act (CSDPA) to assess whether any assistance and or services are required to meet the needs of a disabled child and or to support parents looking after a disabled child.

6. Education and health care plans

The Children and Families Act 2014 and The Care Act 2014 defines the way in which health and social care is delivered for children and young people with special educational needs and disability (SEND).

When providing support for a child or young person with SEND, NCCG and LBN should endeavour to work together to assess, coordinate a jointly agreed package of Continuing Care and, in doing so and if applicable, inform the health needs of the child’s and young person’s education, health and care plan (EHCP). It is essential that all professionals understand how children and young people’s continuing care is assessed and delivered and what other health services are provided when children are not eligible for continuing care.

4 https://www.legislation.gov.uk/ukpga/2006/41/contents
5 http://www.newhamccg.nhs.uk/services/transforming-care.htm
6 http://www.newhamconnect.uk/Services/3330
The appropriate care of children with profound, and multiple disabilities or chronic severe illness generally involves input from all statutory agencies: health, social care and education. High quality care for this small group of children with complex needs depends on timely, comprehensive interagency assessment and co-ordination of services.

The needs of children or young people of compulsory school age differ to adults because of their right to appropriate education provision. This is evidenced by a child’s educational needs and the dependency of children on their primary care givers. This means families will require support from health, education and social care provided through joint working between the agencies but with each agency being responsible for meeting the cost of their respective contribution to the care package.

If a child or young person is assessed as no longer eligible for Continuing Care services the care package may not continue. A plan should be put into place offering other options for support. Under the Children & Families Act 2014, a child, or young person with SEND requiring support beyond that available in a typical mainstream school may have an EHCP.

7. About children’s continuing care

Children and young people may be eligible to receive continuing care funding for a variety of reasons such as needs arising from congenital conditions, long-term deteriorating conditions, accidents or the after effects of serious illness or injury. The children’s decision support tool (DST) appendix 2 sets out children’s needs across ten care domains, divided into different categories of need:

- Breathing
- Eating and drinking
- Mobility
- Continence and elimination
- Skin and tissue viability
- Communication
- Drug therapies and medicines
- Psychological and emotional needs
- Seizures
- Challenging behaviours

Continuing care packages are offered in the child or young person’s home, or as a contribution to their placement in a residential school, residential placement or to fund hospice care. These are agreed in local funding panel including with LBN. If a package is needed for end of life care, this can be agreed outside the panel process, using a virtual process, to ensure no delay to provision.

The national framework reinforces the fact that NHS continuing care for children and young people may be for a finite period as a person’s condition may alter over time. Eligibility is therefore based on the assessed levels of need and regular reviews are built into the process to ensure that the care package is needed and/or continues to meet the individual’s needs. Diagnosis of a disease or condition is not in itself a determinant of a need for continuing care.

Individuals and their family/carers will need to understand the process for assessment and provision of continuing care and to participate in the process wherever possible. Children, families and carers are integral in developing a more personalised approach to care.
8. Newham children’s Continuing Care process

The national framework for assessing children’s continuing care is described by a pathway. This pathway outlines processes and timeframes for:

- Assessment
- Decision making
- Arrangement of provision
- Ongoing review

The clock starts at the point of recognition that a child or young person should have a full continuing care assessment (i.e. following any pre-assessment or screening). The family will be given a clear timescale and should expect a decision on eligibility for continuing care within 6 weeks.

However, given the complexity and variety of needs which a CCG and health services may be assessing, there should be scope for flexibility. For example, if an assessment is being made pending a child’s discharge from hospital which is not planned for several months, other assessments may be reasonably given priority. In cases of very complex needs, there may be a number of professionals involved e.g. a need for a simultaneous social care assessment. If the child or young person is being discharged from acute care or tertiary care adherence to a clear timetable increases the likelihood of the child or young person being discharged in a timely manner and reduces potential for a delayed discharge.

A continuing care assessment should not however be delayed in order to fit within the timescale for an EHCP. A decision on whether or not a child has a continuing care need can be made by the children’s continuing care panel, and notified to the local authority SEND co-ordinator, as part of the health advice for an EHCP. The package of care can subsequently be incorporated as part of the EHCP planning process, which would also provide a basis for determining which commissioner is responsible for what types of care, and reaching multi-agency decisions.

Any extensions of time required for a continuing care assessment will be discussed with the family and clear explanations given. If the child/young person does not have an allocated social worker, then the nurse or continuing care assessor will make a referral to LBN to undertake a joint assessment. A joint assessment will be delivered to help inform joint planning and any potential joint care package wherever possible.

The continuing care process should focus on the child or young person in the context of their family and community and considering their needs by age e.g. when moving from nursery to primary, secondary school, school to college and from childhood to adulthood.
### Table 1: Children’s Continuing Care timeline

<table>
<thead>
<tr>
<th>Phase</th>
<th>Step</th>
<th>Summary of Key Actions</th>
<th>Timescales</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment</td>
<td>Identify</td>
<td>A child or young person with a possible continuing care need is referred to the CCG or delegated provider</td>
<td>Clock Starts</td>
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<tr>
<td></td>
<td></td>
<td>[Pre-assessment]</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>A child or young person’s health assessor is nominated, and the process of assessment begins</td>
<td></td>
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<tr>
<td>Assess</td>
<td></td>
<td>The health assessor undertakes the assessment, comprising four areas:</td>
<td></td>
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<td></td>
<td></td>
<td>- preferences of child or young person and their family;</td>
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<tr>
<td></td>
<td></td>
<td>- holistic assessment of need;</td>
<td></td>
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<td></td>
<td></td>
<td>- reports from multi-disciplinary team;</td>
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<td></td>
<td></td>
<td>- Decision Support Tool for children and young people</td>
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<tr>
<td>Recommend</td>
<td></td>
<td>The health assessor completes the process of assessment, and makes a recommendation</td>
<td></td>
</tr>
<tr>
<td>Decision-</td>
<td>Decide</td>
<td>The multi-agency forum considers the recommendation and decides if the child or young person has a continuing care need</td>
<td></td>
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<tr>
<td>making</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arrangement</td>
<td>Inform</td>
<td>The child or young person and their family are informed of the decision. Development of costed package of care. This process will draw on use of best practice resource allocation tools that identify appropriate levels of care for children who meet continuing care criteria. These tools include the Bradford Scale and CCHAT tool. Any relevant organisations, such as the local authority, and key health professionals involved in the child or young person’s care (e.g. GP, paediatrician) should also be notified.</td>
<td>6 weeks</td>
</tr>
<tr>
<td>of provision</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deliver</td>
<td></td>
<td>Commissioning of the package of care and its provision to the child or young person. Ongoing monitoring / contract management for the commissioned service</td>
<td></td>
</tr>
<tr>
<td>Ongoing</td>
<td>Review</td>
<td>Reassessment of the child or young person’s continuing care needs Timeframe for review is three months following initial assessment and annually as a minimum thereafter</td>
<td></td>
</tr>
</tbody>
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### 8.1 Access to continuing care

All enquiries relating to children with complex needs, or continuing care needs, or referrals for continuing care assessment will be directed to the children’s continuing care team (CCNT), provided by ELFT, or the CAMHS continuing care assessor (also provided by ELFT) who will act as the single point of contact, as defined in the national framework.

The provision of continuing care for children and young people is dependent on:
- The child or young person is under the age of 18 years
- The child or young person has complex health needs that include behavioural, emotional, mental health, and physical needs.
- The child or young person has identified health needs which cannot be met by existing universal, targeted and specialist health services.
- A checklist (screening tool?) indicates the need to progress referral to a full assessment to establish eligibility for continuing care.
- The child or young person has a rapidly deteriorating condition which requires a care package to support end of life care.

8.2 Referral

All referrals should go directly to the ELFT CCNT or CAMHS dependent on whether needs are primarily focused on physical or psychological needs. It is the responsibility of the referrer to identify health needs not met by universal, targeted and specialist services to prevent any delays in the process.

8.3 Assessment

The continuing care nurse (CCN) or continuing care assessor as lead assessor will follow a pre-assessment process (appendix 1) which considers the necessity of carrying out a full continuing care assessment using the DST. This pre-assessment will draw on elements of the formal process, considering the evidence of the child or young person’s needs as presented by professional advice, considering where those needs might lie, and examining any existing package of care.

The child or young person being considered for continuing care should, where possible, understand the continuing care process, and receive age appropriate and accessible information. This will maximise the child or young person’s ability to participate in a meaningful way about the care they receive. This also means that the child, or young person’s own perception of needs, where able, should be at the heart of the continuing care process. Their wishes and expectations of how and where care is delivered should be documented and considered; and their preferences should be considered alongside the benefits and risks of different types of provision. For children, too young to express their own views, parents views, and preference will also be recorded.

Parents and carers are also key in supporting the assessment. As primary carers they provide much of the care to the child or young person. Care packages should build on this, and not replace the role as primary care giver completely.

Once a decision has been made to proceed to full continuing care assessment the aim is for the decision to proceed and outcome of the assessment be given to the child, young person, and their family within 6 weeks. If the child or young person is being discharged from acute care or tertiary care, then the assessment process must be completed in a timely manner to reduce potential for a delayed discharge.

There are four areas of the assessment:

A. The preferences of the child or young person and their family
B. Holistic assessment of the child or young person and their family, including carer assessment
C. Reports and risk assessments from the multidisciplinary team
D. The children’s decision support tool. The fourth area brings together the assessment information from the three other areas. It is not a stand-alone tool and is designed to
ensure that relevant needs are assessed, captured and described in a consistent way

8.4 Eligibility criteria

Eligibility must be based on assessed levels of need, identified through the use of the DST to ensure consistent and comprehensive consideration of children and young people’s needs over 10 care domains.

Eligibility for continuing care is based on:

- A score of priority in one or more domain
- A score of severe in one or more domain
- Scores of high in three or more domains

Please note the above criteria are for guidance only, and exceptional cases will be considered.

8.5 Decision making

Following the assessment phase, recommendations are presented to the children’s continuing care panel to decide whether continuing care thresholds are met. Parents, carers and the young person themselves should be informed of the panel decision and given a clear explanation of the rationale for decision. This should be sent in writing by the panel administrator within 5 working days. The letter should include the complaints procedure in case the panel decision reached does not meet a child or family’s preferences and/or expectations. Key professionals, such as the child’s paediatrician, or multi-disciplinary team or GP, and key organisations, such as their school and local authority, should also be informed.

When a child is found not to meet continuing care thresholds, a clear rationale for the decision should be provided to the child, young person and their family. In this instance, their needs should be addressed through existing universal and specialist services using a case management approach.

8.6 Preparation of recommendations

Following the completion of the assessment by a nominated children and young people’s health assessor and confirmation that a child or young person is eligible for continuing care, recommendations and costed options are produced for consideration.

A resource allocation tool will be used to develop an appropriate care package i.e. a suggested number of hours of care. Newham uses two nationally recognised tools to help consider the allocation of resources, the CCHAT and Bradford Tools (see appendix 3). These tools are used as a guide for the development of new packages and to inform care package changes following re-assessment. These are considered alongside input from the child, young person and parent/carer to establish what care package might help meet identified needs. Care packages are always considered on a case by case basis as the needs and wider context differs for every child or young person.

Costs for the provision of care packages are sought from a minimum of three health and care agencies.
All aspects of the assessment must be transparent, fair, and consistent. Careful consideration should be given to whether there is potential for independence or change in the child, a young person’s need for a package of care i.e. the child, young person has recently been discharged from hospital and requires a care package temporarily.

8.7 Integrated panels

London Borough of Newham’s (LBN) eligibility criteria for specialist social care services for disabled children and young people 0-18 October 2015 states that ‘there is a general duty to provide services under the Children Act 1989, Part II, which is triggered by LBN determining that the provision of services is appropriate and necessary to the assessed needs of a child/young person. There is an enforceable duty under the Chronically Sick & Disabled Persons Act 1970’ (s2).  

Multiagency panels are held in Newham on a monthly basis and comprise of professionals from health, education and children’s social care. Each panel is responsible for considering individual applications for funding of care and support in the following areas:

- Complex Needs Panel – considers and develops joined up plans for children with complex needs across two of the three agencies (health, social care or education).
- Child Integrated Resource Panel (CHIRP) – considers and agrees CCG and LA funding responsibilities and establishes bipartite or tripartite funding where applicable.

8.8 Arrangement (brokerage) of provision

NHS Contracts are in place between the CCG and agreed provider/s for the delivery of children’s continuing care packages. A written agreement will also be in place between the provider commissioned to deliver the care and the family using a parental contract which allows for flexible and personalised care.

Relevant providers should be informed of the panel decision to allow the package of continuing care to begin as soon as possible once the decision has been made, and the child or young person and their family has been informed.

Newham commissioners with ELFT will make the necessary logistical, funding and, in some instances, contractual arrangements to initiate the delivery of the package of continuing care, with the support of the continuing care nurse / assessor.

Arrangements to jointly fund packages of care across NCCG and LBN are considered on a case by case basis. The further development of policy and local arrangements is in progress.

8.9 Ongoing review process

All packages of care will be subject to review, looking at the developing needs of the child or young person continue to be met. Reviews are at three months following the start of a package and then annually at minimum, or in line with transition to appropriate services or as changing needs dictate.

The responsibility to commission care is not indefinite; as needs change eligibility may change as well. In instances where transition back into universal or specialist services is appropriate, the child or young person and their family should be supported throughout this

transition, ideally from within their existing care team. Early engagement with other services is essential for proactive planning and ensuring a smooth move to other services. The child or young person, their family or carer also reserve the right for a review sooner if it is felt that health needs have changed prior to the planned review date.

9. Hospital Care

Should a child or young person require an admission to hospital the care workers or nurses working on their care package can support them while admitted to hospital, or in attending outpatient appointments. Having a familiar face while in hospital or attending clinics is known to benefit children in terms of continuity of care and alleviating child and parental stress in times of acute illness, but also in facilitating an early and well planned discharge. Each child will require their own individual plan for admission to hospital, discharge from hospital, and attending hospital appointments. This plan will need to be agreed by all key agencies providing planned care for the child or young person, and their family/carer including the usual hospital; and the care package agency

9.1 Discharge Planning

Risk assessment and care plans are central to successful discharge for children, young people and their families/carers.

The process of planning discharge from hospital to home is also dependent on a number of key agencies working together in an integrated way. This helps prevent delays to discharge, the arrangement of inflexible care arrangements, and supports parents/carers in being fully competent in meeting the child or young person’s needs. Discharge will be facilitated by a ‘whole systems’ approach to assessment and the commissioning and delivery of services. The multi-disciplinary team (MDT) will work together in an atmosphere of collaboration and co-operation. The needs, wishes and rights the child, young person and parents/carers will be paramount throughout the process. Discharge planning should commence at the earliest opportunity, if possible prior to admission, and no child or young person should be discharged until it is clinically safe to be discharged to another setting or return home. Conversely no child should remain in hospital when it is clinically safe to return home or to another setting, because of delayed and/or ineffective discharge planning.

9.2 Step down Care

It is accepted that for some children with highly complex needs e.g. long term ventilation (LTV), palliative care needs, or rehabilitation needs, organising care, equipment, training care workers or nurses and parents, can go beyond the child/young person’s hospitalisation period. These care packages, although rare may require a stepdown approach in another hospital setting for LTV needs (NHSE funded), hospice setting for palliative care (CCG funded), or a rehabilitation setting (usually NHSE funded) which can last for varying timeframe dependent on needs but should always include a gradual reduction in the step down care to facilitate a return home. These cases will be discussed, agreed and closely monitored on a case by case basis.

9.3 Section 117 (Mental Health Act 1993)

Section 117 outlines the duty of clinical commissioning group and local social services authority (in cooperation with relevant voluntary agencies) to arrange for the provision of (or in the case of the local social services authority, provide) after-care services for any person to whom section 117 applies. This duty lasts until such time as both of organisations are satisfied that the patient is no longer in need of any such services. The duty does not cease if a patient remains subject to a Community Treatment Order under section 17A).
The duty under section 117 applies to people of all ages, including children and young people who are detained under sections 3, 37, 45A, 47 and 48, and who are subsequently released from liability to be detained in hospital or who have been granted leave of absence by virtue of section 17. Access to funding for these children is through a separate route led by East London Foundation Trust. Children or young people are most likely to be eligible for section 117 support if they have been in hospital under section 3 of the same mental health act.

When making decisions in the child’s interest advice and support will be sought from an advocate for the child.

10. Bespoke requests

Bespoke equipment, therapies (assessment and treatment) including CAMHS for children looked after, and specialist assessment not available within local or NHS England funded provision may also be funded. NHS England8 ‘Who pays’, provides guidance on determining who ‘the responsible commissioner’ is for children who have moved of area but still have a Newham GP. This can apply to a looked after child placed out of area, or a child whose family have moved to a new area. For children looked after, the responsible commissioner is determined by the location of their GP at the point they became looked after.

11. Access to specialist (tertiary) care

The specialised services commissioned by NHS England have been grouped into six National Programmes of Care (NPoC). Each has an NPoC Board which coordinates and prioritises work across the services in that programme of care.

The six NPoC’s are:

- Internal medicine – digestion, renal, hepatobiliary and circulatory system
- Cancer
- Mental health
- Trauma – traumatic injury, orthopaedics, head and neck and rehabilitation
- Women and children – women and children, congenital and inherited diseases
- Blood and infection – infection, immunity and haematology

Within these programmes of care will be specialist services for children such as inpatient mental health services and rehabilitation services for children with an acquired brain injury. Access to services can be looked into by local health services and commissioners.

12. Individual Funding requests

An individual funding request (IFR) is a request to fund clinical interventions or treatment that falls outside existing CCG/NHSE contracts and commissioning arrangements and where funding needs to be considered on an individual basis. These are exceptional requests and the application process is as follows.

An appropriate IFR is where:

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A child or young person's treatment falls outside generic or treatment-specific policies where an unusual ('exceptional') clinical circumstance applies to the individual child or young person.

A particular treatment or intervention could benefit a child or young person with a very rare clinical condition. This might include:

- Interventions not or not yet supported by NICE
- Requests to continue funding for patients previously treated:
  - by self-funding
  - through funding from the device manufacturer or pharmaceutical industry, provider trusts treating at their own risk, on compassionate grounds
  - through a decision made by another CCG commissioner where the child or young person has become the commissioning responsibility of a CCG covered by the terms of the NCCG policy.

Requests for referral to a service not commissioned locally and not listed on the national menu (including applications for overseas treatment) excluding NHS services directly commissioned by NHS England.

IFR cannot be used to fund ongoing treatment for a child or young person whose treatment has started as part of a clinical trial.

All documents (IFR, PoLCV, IVF polices and application forms) are available on the CCG website:
http://www.newhamccg.nhs.uk/search.htm?search=IFR&sitekit=true&indexname=WWW&task=search

13. Fast track

End of life care refers to a rapidly deteriorating condition characterised by an increasing level of dependency, whereby the lifespan is thought to be days or weeks rather than months or years. Any child or young person deemed to be requiring end of life care will require a Fast Track assessment for immediate provision of care. In these cases, the ‘children and young people’s continuing care fast track’ documentation will be completed by the appropriate professional and sent to NCCG.

The CCG lead for children will action the fast track assessment and recommendation immediately and determine, agree and/or arrange appropriate provision as requested by the CCN. In emergency cases, the CCN or any other person acting with the authority of NCCG, can agree EOL care provision within 48 hrs outside of the usual process with notification and discussion.

Children and young people who require fast track care because of the nature of their needs, such as a prognosis indicating end-of-life care needs, should be identified early and the child or young person’s needs met as quickly as possible. The continuing care process should not restrict access to end-of-life care over a shorter period and should not result in any delay to treatment or care.

Care for EOL will usually have funding agreed for 1 – 2 weeks at a time. This is to ensure the right care is in place for rapidly changing needs and to meet the child and family preferences.
14. Prioritisation

At times, there will be exceptional circumstances which impact on delivery, e.g. outbreak of flu, or an emergency response such as providing end of life care. The CCG will apply the following approach to prioritisation of its resources:

I. Children whose conditions carry a high degree of clinical risk, such as those children requiring assisted ventilation, or where the clinical situation is unstable or persistently difficult to manage.

II. Acute deterioration in condition/terminal stages of illness as identified by medical assessment.

III. Potential breakdown of the family unit due to the impact of care responsibilities as identified via a joint care planning meeting or where several professionals involved in the care are raising serious concerns.

IV. Marked increase in the need (end of life care) as identified by a nursing assessment.

This approach will only be applied in exceptional circumstances but could result in changes to some existing care packages to provide emergency support for a child being discharged for end of life care. Families of some newly assessed children may also have their care package delayed. This scenario must be kept under constant review by the CCNT and CCG, so that all care packages resume as soon as it is possible.

15. Transition

Once a young person reaches the age of 18 years, they are no longer eligible for children’s continuing care but may be eligible for adult NHS continuing healthcare, which is subject to its own legislation and specific guidance. It is important that young people and their families are helped to understand that eligibility to children’s continuing care does not automatically imply eligibility to adult NHS continuing health care and the implications of this will be made clear right from the start of transition planning as outlined below:

I. At 14 years of age, the young person will be brought to the attention of the CCG’s adult NHS continuing healthcare team using the continuing care transition notification documentation.

II. At 16 years of age, screening for adult NHS continuing healthcare will be undertaken using the adult screening tool.

III. At 17 years of age, an agreement in principle for adult NHS continuing healthcare will have been made.

IV. At 18 years of age, full transition to adult NHS continuing healthcare or to universal and specialist services will have been made, except in instances where this is not appropriate. Such as when a young person is held in a secure estate accommodated under the Mental Health Act.

V. Where the young person has an allocated children’s disability team social worker, they will lead the transition process, working alongside the identified transition team social worker (part of the 0-25 SEND social work team).

VI. A package of care may change or continue as before, dependent on assessed need, and/or provider of the care package changes.
16. Personalisation

Personalisation and child centred planning is the driver for any continuing care process. The level of support required by each child, their family or carers will vary and may change quickly. It is often dependent upon their own resilience, the psychosocial dynamics and emotional needs within the home, other networks of support in place as well as the child’s own medical care requirements.

The shaping of services around the individual needs and wishes of children, young people and their families, and carers has become central to health and social care policy. Choice and control offered by personal health budgets (PHBs) can significantly improve quality of life and lead to improved outcomes for children and young people.

All children/young person’s (or their family) eligible for continuing care can receive information on PHB’s, including their indicative budget. If the family wish to have a personal health budget, interim support can be arranged until the personal health budget can be set up. If the family wish to have a personal health budget a PHB request form will be filled in and submitted to the CCG. This will be followed up by a visit to the family by the CCN to develop the care plan and agree outcomes. The type of PHB the family are interested in will also be agreed.

Different personal budgets:

**Direct payment** made to the young person or their family. This may be a via issue of a payment card to enable the young person or family to broker their own care, through the set-up of a dedicated bank account to pay carer’s directly and/or employ carer’s.

The agreement of a notional budget to be spent by the CCG following discussions with the child or young person, and their family (or other representative) as to how best to secure the provision they need. This would mean a family understands the costs of the care they receive and have greater input into how they can best use their budget.

A brokered budget held by a third party who brokers the care package in a way agreed between the CCG and the child or young person, and their family (or other representative)

Or a combination of the above options.

NCCG are further developing their personal budget offer and while this work is progressed it is advised that children, young people or their parent/carer discuss PHB options with the CCN or CCG lead for children in the first instance.

17. Disputes, and escalation process

Where possible, parents, or carers should be given the opportunity to engage in discussions relating to assessment and eligibility. Parents and carers should also be given clear written information as to whether the assessment of need meets the eligibility criteria for children’s
continuing care, or an explanation regarding why thresholds for continuing care were not met. Local processes will also be outlined on the Newham SEND local offer site.  

17.1 Safeguarding

Because the continuing care process is dependent on the full participation of the parent or carer’s in the process, inability or refusal to be involved with this pathway cannot be considered a reason for not making recommendations about a care package. For example, a parent of a child who is tracheostomy ventilated may not wish to receive continuing care support. In such circumstances a risk assessment should be undertaken as part of a continuing care assessment to ensure that the child, or young person’s health needs are not compromised nor that they are put at risk of harm.

If staff suspect neglect and or abuse is happening and or has happened appropriate action will be taken to protect the child in line with Newham safeguarding children procedures. In all cases where neglect and abuse is suspected, the child's GP and the professional network caring and supporting the child will be notified by the member of staff identifying the concerns.

17.2 Organisational dispute process

Continuing care arrangements, in relation to health, social care and education, have the capacity to generate disagreements about agency responsibilities and agency funding. Where organisational disputes over care provision arise, resolving disputes between NCCG and LBN is the overarching aim to ensure that an individual’s potential eligibility for continuing care is correctly determined and that an appropriate package of care is agreed and commissioned.

The agreed arrangements for dispute processes will therefore be based on the following principles and where it is determined that NCCG are the responsible commissioner: -

I. Neither, NCCG or LBN will unilaterally withdraw from funding an existing package.
II. The child/young person will be discharged from hospital as soon as it is deemed clinically appropriate to a step-down setting, or home.
III. NCCG and LBN will work together to agree case management arrangements to ensure the child or young person continues to receive the best possible care.
IV. A placement will be funded outside of the joint panel, without prejudice, if necessary.
V. Packages of care will be funded following discharge from hospital outside of the panel process.
VI. The Local Authority will in accordance with statutory guidance and as appropriate undertake a full assessment.
VII. Responsibility and disaggregation of funding will be based on the continuing care and Local Authority assessments of need.

17.3 Assessment appeals procedure

The first point of contact for the assessment process is the manager of the CCNT. Contact should be made within one month of the assessment or panel decision. It is the CCN role to visit the family again to discuss the rationale and give clear reasons for the assessment process and/or decision. This can be for the initial screening assessment or full continuing care assessment.

9https://www.newham.gov.uk/Pages/Category/Special-educational-needs.aspx
The CCN will go through the assessment tool with the family, looking at additional information to update the assessment. If there remains a dispute with the assessment process the family can request in writing to the commissioning lead for children’s continuing care a review of the assessment by another NHS Provider. This request should be made within one month of feedback on the most recent continuing care assessment.

17.4 Appeals against panel decisions

The Head of Commissioning & Transformation for Children and Maternity will be the first point of contact for all complaints or disputes relating to decisions made in relation to the panel process and eligibility for children’s continuing care. The CCG will endeavour to resolve all disputes and complaints through a local resolution process, within a very short period. In most cases the CCG will try and arrange a convenient time to meet face to face with the family. The commissioner will be supported by the CCG safeguarding lead to review the panel decision.

If there remains a dispute following the commissioner’s review of the panel decision, the family can request in writing a review of the assessment by an independent provider. This request should be made within one month of the CCG review. The independent review will aim to be completed in 30 working days. The outcome of the independent provider’s assessment should be communicated in writing to the parent or carer and individual within 7 working days of the completed assessment.

17.5 Complaints regarding provision

Complaints relating specifically to service provision from ELFT should follow the local Trusts process through the Patient Advocacy Liaison Service (PALS) and then complaints procedure of the National Health Service Complaints (England) Regulations 2009. This will be undertaken with the full involvement of the lead NCCG commissioner and Matron for the CCN Team.

If dissatisfied complainants may contact the ‘Parliamentary and Health Service Ombudsman’ (PHSO), to request an independent review of their case. This must be done within a year after the day on which the person aggrieved first had notice of the matters alleged in the complaint, unless the PHSO considers that it is reasonable to review the complaint outside of this timescale. This request can be made in the following ways: Telephone the PHSO on 0345 015 4033, or submit a complaint via the website, http://www.ombudsman.org.uk/make-a-complaint/contact-us.

Complaints regarding provision from non NHS Trusts should be actioned in accordance with the providers own complaints process, with full involvement from the lead commissioner and CCN undertaking the assessment and planning process.

18. Quality and assurance

18.1 Monitoring delivery

The implementation of this policy will be monitored by the Head of Commissioning and Transformation for Children and Maternity who will act as the CCG lead for children’s continuing care. Key responsibilities include monitoring:

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- Provision of continuing care.
- Any potential risk relating to delivery of care.
- Ensuring that all safeguarding issues are raised in accordance with local and national policy with the CCG’s designated Safeguarding Nurse or Doctor.
- Any issues relating to care as assessed by the nursing team.
- Quality of care packages.
- Contracting of care, including cost and brokerage.

In addition to the formal individual review process, each package of care will be monitored to identify whether providers are delivering in accordance with the NHS standard contract agreement. This will include providers submitting a quarterly report on the activity provided for each individual case. Contract monitoring will be formalised routinely with all providers to maintain adherence to quality and governance standards. NCCG will monitor all contracts held directly with providers of continuing care packages. ELFT will be responsible for the contract monitoring of contracts they hold directly with providers of continuing care packages.

18.2 Quality of provision

The assessment and provision of children’s continuing care is a complex and highly sensitive area which can affect children, young people and their families at a difficult stage of their lives. It is therefore essential that the process is carried out utilising the principles of the 6Cs: care, compassion, competence, communication, courage and commitment and supports individuals, their families and staff to provide the best possible service (NHS England Operating Model for NHS Continuing Healthcare, NHS England, 2015) 11

18.4 Equality impact assessment (EIA)

Newham CCG has a duty to have regard to the need to reduce health inequalities in access to health services and health outcomes achieved as enshrined in the Health and Social Care Act 201212. Newham CCG is committed to ensuring equality of access and non-discrimination, irrespective of age, gender, disability (including learning disability), gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex (gender) or sexual orientation. In carrying out their functions, Newham CCG will have due regard to the different needs of protected equality groups, in line with the Equality Act 2010.13

18.5 The Mental Capacity Act (MCA 2005 Code of Practice)

The Mental Capacity Act 14 applies to those over the age of 16. The Children Act 1989 and 2004 15 is the legislative framework for decision making for those under the age of 16. The Mental Capacity Act 2005 empowers people to make decisions for themselves wherever possible and to protect people who lack capacity. Whether people have or lack capacity, the person in question must remain at the heart of the decision making, including involving the person who lacks capacity as much as possible. When making decisions in the child’s interest advice and support will be sought from an advocate for the child. Where decisions need to be made for a person who lacks capacity these decisions must be made in their best interest. The Act also allows people to make decisions whilst they still have capacity for time in the future where they may lose capacity. All organisations and individuals who look after

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12http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted
or care for someone who lacks capacity to make decisions are required to comply with the act. For more details see the Mental Capacity Act Code of Practice.

18.6 Deprivation of Liberty

The Deprivation of Liberty Safeguards 200716 relates only to people aged 18 or over. If the issue of depriving a person of liberty arises, other safeguards must be considered – such as the existing powers of the court, particularly those under section 25 of the Children Act 1989, or use the Mental Health Act 198317, and their subsequent replacements.

18.6 Safeguarding

The assessment of children and young people for continuing care must take account of safeguarding policies and legislation, which place a duty on all agencies to safeguard and promote the welfare of children and young people. The voice of the child or young person will be sought by the social worker and CCN at or around the time of assessment; and for each review that takes place. Where there may be communication difficulties or other reasons for making it difficult for the voice of child to be heard, the family and local authority and health professional will help to provide the child’s view.

Exceptionally, information may be withheld from a child or young person or someone with parental responsibility for them if the CCG considers that it would be likely to cause significant harm to the physical or mental health or condition of the child or young person or would otherwise not be in their best interests. Social services should be involved, if they are not already, where it is thought that the child is at risk of significant harm or is suffering significant harm.

If staff suspect neglect and or abuse is happening and or has happened appropriate action will be taken to protect the child in line with Newham safeguarding children procedures. In all cases where neglect and abuse is suspected, the child’s GP and the professional network caring and supporting the child will be notified by the member of staff identifying the concerns.

18.7 Social Care Legislation

Statutory social care services for children and young peoples are provided under the Children Act 1989, following an assessment under the ‘Framework for the Assessment of Children in Need and their Families’. Each local authority providing children and young people services set its own eligibility criteria for social care and therefore, children and families experience different thresholds too. In contributing to a continuing care package for a child, young person it is acknowledged that Local Authorities are only able to legally fund provision within the remit to provide under the National Assistance Act 1948.

Both the Children’s National Service Framework (NSF) (2004)18, the Framework for the Assessment of Children in Need and more recently, guidance for children under three years old who are disabled or have complex health needs, advocate multiagency comprehensive needs assessment and joint planning of care with integrated provision to help maximise children and young people’s development and achievement in life. Likewise, the Disability

Discrimination Act (2005)\textsuperscript{19} makes it unlawful to discriminate against disabled children with a physical or mental impairment where that has a substantial long-term adverse effect on their ability to carry out normal day-to-day activities. It is therefore the principle that assessment of need is carried out in partnership with all relevant agencies.

**Newham’s Continuing Care Flowchart**

1. **Referral to CCN Team**
2. **Initial screening**
   - If child meets criteria proceed to full assessment
3. **Full assessment undertaken using the DST using medical/clinical reports, parental view, therapies, nursing assessment, young person, and child if appropriate**
4. **Does not meet criteria**
   - If no - inform family & referrer
5. **If child meets criteria proceed to full assessment**
   - Present to Children’s Continuing Care Panel
   - Discuss package with family, including PHB
   - Brokerage of care package
   - Review at 3 months point, then annually thereafter
6. **LBN Complex Needs Panel if needs joint planning**
7. **CHIRP Panel if joint funding is required**

\textsuperscript{19}https://www.legislation.gov.uk/ukpga/2005/13/contents
19. Appendices

- Appendix 1 - Continuing Care pre-assessment tool
- Appendix 2 - National Framework Decision Support Tool document (DST)
- Appendix 3 - CCHAT and Bradford Tools

20. Sources of Guidance

- National Framework for Children and Young People’s Continuing Care 2016
- Who Pays? Establishing the Responsible Commissioner (December 2012)
- Children and Families Act 2014
- Children's Act 1989 & 2004
- Working Together to Safeguard Children: revisions to statutory guidance 2018
- Children’s National Service Framework 2004
- Disability Discrimination Act 2010