

CHILDREN'S CONTINUING CARE STANDARD OPERATING PROCEDURE

Policy Author(s)	Alison Sutch Complex Care Children's Nurse. Developed in conjunction with the Cheshire and Merseyside Children's Continuing care Network Group.
Accountable Manager(s)	Jan Snoddon, Chief Nurse
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Applicable Statutory, Legal or National Best Practice Requirements	<p>Department of Health (2010) National Framework for Children and Young People's Continuing Care. http://www.nhs.uk/CarersDirect/guide/practicalsupport/Documents/National-framework-for-continuing-care-england.pdf</p> <p>Department of Health (2016) National Framework for Children and Young People's Continuing Care https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/494230/children-continuing-care.pdf</p>
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1. Children and Young People's Continuing Care Policy for Halton

1.1 Purpose

The purpose of these operating procedures are to ensure that NHS Halton Clinical Commissioning Group (HCCG) and Halton Borough Council (HBC) have a joint consistent decision making process for allocating resources to meet the continuing care needs of children and young people in a transparent, fair and equitable manner. In particular, where a child/ young person has a special educational need or disability (SEND), then HCCG and HBC should coordinate the assessment and agree a package of continuing care, as part of the process to develop the Child/ young person's Education, Health and Care Plan.

Essential elements are;

- a child and family centred continuing care process is in operation for the Halton health and social care economy that follows the principles and approach of the National Framework but also makes sense in the local situation;
- a joint, consistent and transparent approach to assessing care needs and commissioning and providing services in the light of those needs;
- guidance to local practitioners with the knowledge and tools to follow the process;
- To embed within the EHC plan a co-ordinated assessment of a child or young person's Continuing Care needs based on multi-professional input and focused on the outcomes which make the most difference to the child or young person and their family.
- transition arrangements are in place from children's to adult services;
- clarity on remit, membership and working practices of the Complex Needs Panel;
- an appeals process is in place;
- that a joint protocol exists which clarifies respective funding responsibilities of HCCG and HBC;
- a robust process for resolving disputes is in place between agencies.

1.2 Background

In March 2010 the Department of Health (DOH) published the 'National Framework for Children and Young People's Continuing Care'. The National Framework sets out a process for assessment and agreement of eligibility for continuing care. This has been superseded in January 2016 by the DOH document revised "National Framework for Children and Young People's Continuing Care". This latest framework takes account of the new structure of the NHS commissioning created by the Health and Social Care Act 2012, the new integrated approach to commissioning of services for children and young people with SEND which the Children and Family Act 2014 has introduced and the changes to adult social care introduced by the Care Act 2014.

Continuing care for children and young people is needed where a child or young person (under 18) has complex needs which cannot be met from the health services routinely commissioned by NHS Halton Clinical Commissioning Groups (HCCGs) or NHS England. It has been defined in recent regulations as:

*'a package of care which is arranged and funded by a relevant body for a person aged 17 or under to meet needs which have arisen as a result of disability, accident or illness.'*¹

The care needed may be resource intensive, and long-term, with a significant element of nursing care. It may be provided in a number of settings and may involve more than one provider.

Children's continuing care differs from adult NHS continuing health care which applies to anyone from 18 years of age who needs to be considered for a health funded package of care that will be arranged and funded solely by the NHS. Children and Young people's Continuing Care should be part of a wider package of care, agreed and delivered in collaboration between health, education and social care. The new arrangements for children with special educational needs or disability (SEND) in particular provide a framework for outcomes-focused joint assessments involving different partners across education, health and care, and many children and young people who need continuing care will have special educational needs or disability. A decision on whether or not continuing care is needed must be informed by a clinical understanding of a child or young person's condition and an understanding of the way in which their needs affect their lives and those of their family. The emphasis should be on understanding the outcomes which would make the biggest difference to the child or young person and their family, and how health services can support delivery of those aims.

HCCG is responsible for leading the process of identifying the continuing care needs of a child or young person in Halton, continuing care needs should be identified, and the package of care agreed, as part of a holistic assessment of the child or young person's needs. The subsequent decision about provision of care is made in collaboration with the child or young person's health professionals, social care professionals, education professionals and the child/ young person and their family.

1.3 Health Benefit

The evidence suggests that the number of children with continuing care needs is increasing, largely because of technological advances and improved treatments. Continuing care packages which support the care of children with complex needs at home and short breaks can prevent family breakdown, improve the health of the child and the health of their parents/carers; prevent unnecessary A&E attendances and hospital admissions and reduce delayed discharges.

1.4 Eligibility / Thresholds for Service Provision

Some children and young people (up to their 18th birthday), may have very complex health needs. These may be the result of congenital conditions, long-term or life-limiting or life-threatening conditions, disability, or the after-effects of serious illness or injury.

These needs may be so complex, that they cannot be met by the services which are routinely available from GP practices, hospitals or in the community commissioned by

NHS Halton Clinical Commissioning Groups (HCCGs) or NHS England. A package of additional health support may be needed. This additional package of care has come to be known as continuing care. However Continuing Care is not needed by children or young people whose needs can be met appropriately through existing universal or specialist services.

HCCG must ensure they adopt an appropriate focus on those outcomes which make a difference to the child or young person, and their family, and consider their wishes, expectations and preferences as regards how and where care is delivered and its impact. This evidence can only be obtained if the child or young person and their family are involved in every stage of the process, and the HCCG, or their service provider, is active in engaging with them and documenting this evidence.

The National Framework for Children and Young Peoples Continuing Care includes a Decision Support Tool, which has been developed to bring assessment information together and present it in a concise, consistent way. It is designed to help ensure that all relevant needs are assessed and captured to inform local decisions about the care needed, across 10 care domains.

It is the responsibility of assessors to advice, and panels to decide, eligibility for continuing care. A child is likely to have continuing care needs if assessed as having a severe or priority level of need in at least one domain of care, or a high level of need in at least three domains of care. Health assessors should be mindful that even if the child or young person is assessed as not having continuing care needs, they may require other healthcare input from universal services or community children/young person's nursing or other specialist services.

2 Introduction

2.1 What is Continuing Care?

A continuing care package will be required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone.

The care needed may be resource intensive, and long-term, with a significant element of nursing care. It may be provided in a number of settings and may involve more than one provider.

The Continuing Care Assessment process should determine if a child's needs are such that they can only be met through a package of continuing care, health care needs should be identified, and the package of care agreed, as part of a holistic assessment of the child or young person's needs.

It is likely that a continuing care package will include a range of services commissioned by NHS Halton Clinical Commissioning Group (HCCG) and Halton Borough Council (HBC) children's services.

For adults - aged 18 and over - the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care and the supporting guidance and tools should be used.

<https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care>

It should be understood that there are significant differences between children's continuing care and NHS Continuing Healthcare for adults, which is subject to a statutory process. 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. Further information on how to support transition is given below.

2.2 The National Framework

National Framework for Children and Young People's Continuing Care 2016 sets out the principles and the process which should be followed by Halton commissioners. The Framework explains that CCGs have a legal responsibility for securing to a reasonable extent the health care which an individual needs, and about the process which should be followed for the equitable discharge of that responsibility for children and young people with complex needs.

The Framework published in March 2010 has supported good practice locally; the principles which underpin it continue to be relevant which has been retained in the latest Framework September 2015, whilst remove duplication. The Children's Decision Support tool has been integrated within the main text.

This guidance sets out the roles and responsibilities of CCGs, a step-by-step guide to making an assessment and decision and a **Children's Decision Support tool** as a resource to support local determination of packages of continuing care.

3. Roles and Responsibilities

3.1 Leadership Role

HCCG is responsible for leading the process of identifying if a child or young person for whom it has commissioning responsibility under section 3 of the NHS Act 2006 has a continuing care need.

HCCGs are responsible for establishing and managing appropriate governance arrangements for the process. The Chief Nurse within NHS Halton CCG has responsibility for continuing care for children and young people, ensuring there is effective liaison with the Halton Borough Council and other partners, as well as ensuring the effective management of the process.

The Halton response is to work to best practice as outlined in the framework.

This includes the workings of the joint decision making panel across NHS Halton Clinical Commissioning Group (HCCG) and Halton Borough Council (HBC) with responsibilities to:-

- implement and maintain best practice;
- ensuring a transparent, fair and equitable process
- ensure that quality standards are met and sustained;
- identify and act upon issues arising in the provision of children and young people's continuing care;
- ensure flexibility to shape strategic commissioning arrangements and the design of services where the process highlights themes such as several children with the same continuing care needs.

3.2 Role of Children's Complex Care Nurse (NHS Halton CCG)

- To act as a point of contact with whom professionals can liaise to discuss a child or young person with possible continuing care needs
- Raising awareness of the continuing care process; Provide training and development opportunities for practitioners, including consultation;
- Promote awareness of the National Framework 2016;
- Provide support and facilitation for children and young people requiring personal health budgets
- Establish and manage the governance arrangements for the process;
- Coordinate a pre-assessment, make a decision to proceed to full assessment and ensure that the family and young person are informed of the decision
- Ensure that the family and young person has been informed regarding the Continuing Care Process
- Ensuring that assessments are undertaken in a systematic and consistent way to ensure equity and transparency;
- Facilitate a robust and effective health assessment for children with Continuing care needs, to inform the EHC plans
- Ensure that children young people with Continuing care needs have appropriate SMART Outcomes, which are reviewed regularly
- Establish a case management and review system for children with complex healthcare needs subject to Continuing Healthcare
- Ensuring that there is enough supporting information to evidence eligibility for continuing care and instigating assessments where appropriate;
- Quality assure all Health Assessments
- Collating the information from health to present at the Continuing Care Panel and sending to the Administrator;
- Informing families and all those involved in the Continuing Care assessment of the panel decision;
- Arranging the package of support including commissioning and contractual arrangements with Halton Borough Council colleagues
- Undertaking reviews of children and young people's continuing care needs.
- To liaison with HCCG finance and executive teams regarding high cost packages

- To review the quality of care packages, ensuring that staff are appropriately trained to deliver support

3.3 The Lead LA Professional role

- Identifying Children and Young People who may have continuing care needs, and discuss with the Children Complex Care Nurse.
- Obtaining consent for the sharing of information and completing referral for continuing care assessment;
- Completing or submitting an up to date Social Work Assessment or CAF;
- Attending the Multi-agency meeting where the Decision Support Tool is discussed and scoring takes place;
- With the Lead Health Professional, make recommendations for a package of care; focusing on those outcomes which make a difference to the child or young person, and their family, and consider their wishes, expectations and preferences as regards how and where care is delivered and its impact.
- Presenting the case to the Continuing Care Commissioning Panel using appendix 7
- On-going case management;
- Contributing to Continuing Care Reviews by reporting any change in need or issues relating to the package of support to the Continuing Care Coordinator as appropriate;
- Contribute to the EHCP detailing the package of care the CYP receives

3.4 The Nominated Health Assessors role

- Ascertaining the Child / Young Person's and/or family's views and preferences;
- Giving an explanation of Continuing Care and the process involved;
- Completing the Continuing Care Assessment and sending to the Childrens Complex Care Nurse for distribution for the Multi-agency meeting;
- Attending the Multi-agency meeting where the Continuing Care Assessment is discussed and scoring takes place;
- With the Lead LA Professional, make recommendations for a package of care; focusing on those outcomes which make a difference to the child or young person, and their family, and consider their wishes, expectations and preferences as regards how and where care is delivered and its impact.
- Presenting the case to the Complex Needs Panel with the support of the Children's Complex Care Nurse.
- The Lead health professional will have been trained in assessing Continuing Care. Panel members will ensure that Lead health Professionals are the most appropriate clinically qualified professional in relation to the needs of the individual.
- Contribute to the EHCP detailing the health care needs of the CYP, health Outcomes and health care plan

3.5 The Nominated SEN Coordinators role

- Identifying Children and Young People who may have continuing care needs, and discuss with the Children Complex Care Nurse.
- Obtaining consent for the sharing of information and completing referral for continuing care assessment;
- Attending the Multi-agency meeting where the Continuing Care Assessment is discussed and scoring takes place;
- Presenting the case to the Complex Needs Panel with the support of the Children's Complex Care Nurse
- Gathering evidence from children/young people/families/agencies to assist with the Sen assessment process which may also be used within the MDT to assess a CYP for continuing care
- To lead on coordinating person centred planning meetings and produce the EHC plan, in coordination with the Children's Complex Care Nurse to coordinate the CYP health needs
- To review the outcomes of EHC plan or statements to promote good outcomes, in collaboration with the Children's Complex Care Nurse to ensure that the outcomes for both process concur
- To guide and advise on personal budgets

3.5 The Administrator's role will include:

- Distributing panel papers to panel members in advance of the panel meeting;
- Note taking at the Children's Continuing Care Panel Meetings;
- Typing up individual panel notes, updating HBC Action and Decisions log, distributing notes to all panel members.
- Schedule reviews and arranging meetings if necessary
- Scheduling contract monitoring meetings;
- Maintains accurate and up-to-date records on the Broadcare system and referral database;
- Informs Children's Complex Care Nurse that a new referral has been received in a timely manner. (see Appendix 1)

4 The Continuing Care Process

There are seven stages a child or young person with possible continuing care needs will pass through during the continuing care process. NHS Halton CCG should ensure there is a clear timeline from referral through completion of assessment to decision, and that progress is measured against this.

1. Identification;
2. Assessment;
3. Preparation of recommendations;
4. Decision-making;
5. Informing about decisions;
6. Arrangement of provision;
7. Review.

This continuing care pathway should aim to link children, young people and their families with community services, hospital-based services, local authority children’s and young people’s services and the third sector to ensure a joined-up and integrated approach to meeting needs

Phase	Step	Summary of key actions	Time-scale
Assessment	Identify	<ul style="list-style-type: none"> A child or young person with a possible continuing care need is referred to the CCG. <p>[Pre-assessment]</p> <ul style="list-style-type: none"> A child or young person’s health assessor is nominated, and the process of assessment begins. 	Clock starts
	Assess	<ul style="list-style-type: none"> The health assessor undertakes the assessment, comprising: <ul style="list-style-type: none"> preferences of child or young person and their family; holistic assessment of need; reports from multi-disciplinary team; Decision Support Tool for children and young people. 	
	Recommend	<ul style="list-style-type: none"> The health assessor completes the process of assessment, and makes a recommendation. 	
Decision-making	Decide	<ul style="list-style-type: none"> The multi-agency forum considers the recommendation and decides if the child or young person has a continuing care need. 	
Arrangement of provision	Inform	<ul style="list-style-type: none"> The child or young person and their family are informed of the decision. Development of costed package of care. 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. 	6 weeks
	Deliver	<ul style="list-style-type: none"> Commissioning of the package of care and its provision to the child or young person. Ongoing monitoring / contract management for the commissioned service. 	
Ongoing	Review	<ul style="list-style-type: none"> Reassessment of the child or young person’s continuing care needs. 	

4.1 Identification

The continuing care process begins when there is recognition that a child or young person may have needs that cannot be met through existing universal or specialist services alone. A child or young person may be referred for assessment through a number of different routes, settings and care pathways.

Referrals can be made by a variety of professionals, and including professionals working in primary, secondary and tertiary care, Child and Adolescent Mental Health Services, community nursing teams, local authority-commissioned public health, school nursing and also education, and social care. This referral should be made using appendix 1 ensuring that consent to share information has also been sort from the child/ young person's parents or guardian (appendix 2). These should then be submitted to Continuing Healthcare via continuinghealthcare@halton.gov.uk. Professionals making the referral should provide evidence to inform the continuing care process.

The Children's Complex Care Nurse will follow a quick pre-assessment process (appendix 3), which considers the necessity of carrying out a full continuing care assessment. 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 in the Children's Decision Support Tool (appendix 4), and examining their existing package of care. A decision on whether or not a child should proceed to a formal assessment will be made quickly, and fully documented and where necessary, agreed with the responsible executive in NHS Halton CCG. This pre-assessment should not take more than 2 working days.

Once a decision has been made to proceed to full continuing care assessment, the aim is for a decision to be given to the child or 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.

Consent to share information should be obtained from parents and partner agencies for all continuing care assessments. Information should be shared fully complying with Halton Borough Council and NHS Halton CCG information-sharing protocols. Advice, recommendations and decisions should be recorded and stored in accordance with Halton Borough Council and NHS Halton CCG recordkeeping policy.

The NHS Halton CCG must ensure that the child or young person and their family being considered for continuing care should understand the continuing care process, receiving accessible advice and information in a timely and clear manner. Their views should be documented and taken into account, and considered alongside the benefits and risks of different types of provision as part of the assessment. Where the views of the child or young person are different from those of their family, the possibility of advocacy should be discussed.

Children and young people who require fast-track assessment because of the nature of their needs (such as a palliative care need) 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 for children and young people who require immediate support over a shorter period, and should not result in any delay to appropriate treatment or care being put in place and will be considered using an extraordinary decision outside of the formal panel.

4.2. Assessment

The assessment phase is the second stage of the continuing care process. The assessment phase should be undertaken in a systematic and consistent way to ensure equity and transparency. This should be led by a children and young people's health assessor, who will draw on the advice of the other professionals. This phase may include a pre-assessment, to determine whether or not a full assessment is necessary. (See Appendices 5, 6 and 7)

There should be **Four Areas of Assessment**

i. The preferences of the child or young person and their family

The child or young person and their family should be supported to be partners in the assessment process; this includes siblings and working partners. Care is often highly invasive of the family home and the preferences of all family members should be sought as far as possible.

ii. Holistic assessment of the child or young person and their family, including carer assessment

The assessment phase is an integral part of the continuing care process, and questioning by a professional can give valuable insight into a child or young person's needs but also reinforce feelings of self-worth in the parents. The carer's assessment should consider the family capacity for resilience; this relates to a family's ability to provide care for the child or young person and is not a judgement on parenting ability. Family circumstances, the health needs of other family members and the proposed environment of care should also be considered.

iii. Reports and risk assessments from the multidisciplinary team

The nominated children and young people's health assessor is responsible for undertaking any necessary healthcare risk assessments that have not already been undertaken and collating the relevant risk assessments and reports (health, social and education).

iv. 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.**

This stage will be undertaken by a nominated children and young people's health assessor which should be a health practitioner with relevant skills and competencies, and the Lead LA Professional in consultation with the Children's Complex Care Nurse from NHS Halton CCG:

The Nominated health assessor is responsible for obtaining:

- Consent to the assessment and consent to obtain and share information
- The preferences of the child or young person and their family
- Collate relevant information, reports, risk assessments and evidence from the multi-disciplinary team to inform the DST
- The nominated health assessor will then arrange a multi-agency meeting to undertake the assessment, discussion and scoring of the DST.
- Holistic assessment of the child or young person and their family; and completing the Children and Young People's Decision Support Tool
- Agreeing recommendations with the Lead LA Professional in consultation with the Children's Complex Care Nurse from NHS Halton
- To facilitate the health input to the EHC plan.

The LA Professional is responsible for:

- Submitting an up to date Social Work assessment or CAF to the Complex Care Panel
- Attending the multi-disciplinary meeting and discussing the scoring for each of the domains; and
- Agreeing recommendations with the nominated health assessor.

The Children's Complex Care Nurse will;

- Ensure that Children and young people's continuing care needs are assessed consistently and fairly, irrespective of the reason for their needs or the nature of those needs.

The EHC plan process has at its heart a co-ordinated assessment of a child or young person's needs, based on multi-professional input, and focused on the outcomes which make the most difference to the child or young person and their family. The views and aspirations of the child or young person, and of their family, are central to developing a holistic view of the child's needs. Any existing plans should be considered prior to the Continuing Care Assessment.

The information needed to make a decision on the continuing care package will be very similar to that needed for the health element of the EHC plan, and consideration should be given to partly integrating the 2 process' without delaying a decision on a package of continuing care

The results of continuing care assessments should be shared with the child or young person and their family. Everyone who contributes to an assessment should be fully aware of its intended use and distribution.

4.3. Preparation of Recommendations;

Following the completion of the assessment by a nominated children and young people's health assessor, recommendations and costed options should be produced for consideration at a multi-agency decision-making forum. The four areas of assessment should provide the evidence for options.

The Nominated Health Assessor should arrange a meeting with the Multi-agency and/or multidisciplinary groups and the family to consider the child or young person's continuing care options, taking into account the child or young person's and their family's preferences, which are safe and effective. Where the child or young person is already has other care packages in place, the team must have regard to these packages of care and seek to work with other teams to ensure that the care provided fits seamlessly with other care being received.

Care planning should begin early, consider discharge needs where appropriate, and be simplified to enable community-based services to provide home-based care wherever possible. Planning of the package of care should consider:

- how continuing care integrates with SEND provision, and existing universal and specialist providers;
- sustainability and long-term outcomes;
- a multi-professional approach, rather than one which focuses on venues of care;
- the child or young person's home as the focus of care. When home care options have been fully considered and ruled out on care, risk or capacity grounds and/or family choice, then residential care should be considered to support home care or to replace it;
- out of hours support;
- staff competency and training of parents, staff and foster carers (including training costs) should be considered as appropriate.

A decision to include long-term residential care in a child or young person's package of care must never be made on financial grounds.

4.4. Decision-making;

Following the assessment phase, the nominated children and young people's health assessor with the support of the Children's Complex Care Nurse should produce recommendations and costed options for the complex needs panel to decide whether continuing care is needed and, if so, what package of continuing care should be provided.

A decision should be made within 14 working days of receipt of the assessment documentation.

4.5. Informing about decisions:

Following the panel's decision, the child or young person and their family should be notified within 5 working days. 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. This should be sent in writing from the Administrator, including their rights and of the complaints procedure in the case of a decision which does not meet their preferences and/or expectations. Which is also published on the Halton Local Offer. <http://localoffer.haltonchildrenstrust.co.uk/education-health-social-care-plan/>

4.6 Resolving disputes

Where a child or young person is found not to have a need for continuing care, a clear written explanation of the rationale for the decision should be provided to the child or young person and family. Using the Quality Assurance Tool (Appendix 5) In this instance, their needs should be addressed through existing universal and specialist services.

Where the child or young person is found to have a need for continuing care but the proposed care package varies from the preferred option of the child or young person and their family, a clear written explanation of the rationale for the decision should be provided.

Continuing Care assessment should be reviewed by the Children's Complex Care Nurse using Quality Assurance documentation, which may be used to resolve disputes

NHS Halton CCG and Halton BC has an agreed dispute resolution process for SEND and this should also be used for disputes relating to children's continuing care, as with their EHC plan, is the strongest means of ensuring a plan meets the child's needs and expectations

4.7 Arrangement of provision

Any agreed provider 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. This should be sent in writing by the administrator.

Halton Borough Council commissioners will lead to 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 NHS Halton CCG.

In some instances there may be an unavoidable delay in implementation, such as where the outcome of a Disabled Facilities Grant panel is required, but NHS Halton CCG health commissioners and HBC should ensure that delays are avoided as far as is possible. As always, the child or young person and their family should be kept informed of progress and involved in implementation.

4.8. Review

The child or young person's continuing care needs should be reviewed three months after the panel decision, and then at least annually thereafter. The Nominated Health Assessor and the LA Lead should be informed of the review date on the day of decision by Complex Needs Panel.

If the child or young person's circumstances are known to have changed, this should also trigger a review, and the child or young person and their family should be able to request a review.

The HBC commissioner and the Children's Complex Care Nurse are responsible for regular contract review to ensure that service specifications are being met and the service being provided is of the required level.

Reviews of a child or young person's continuing care should be an opportunity for assessment of needs and how they are being addressed by the care package. It should be made clear to the child or young person and their family that reviews are designed to ensure that the child or young person's continuing care needs are being met on an ongoing basis and that they are not financially motivated.

Where a child or young person has SEND, the continuing care package review, and the regular review of an EHC plan, should be synchronized.

Any such review should be transparent, involve the child or young person and their family. Both verbal and written reports should be given to the child or young person and family as appropriate.

Reviews should be responsive to changes in a child or young person's fundamental need, as there will be cases where successful management of a condition has permanently reduced or removed an ongoing need; The responsibility to commission care is not indefinite as needs may change and this should be made clear to the child or young person and their family. Equally, commissioners must guard against making changes to a package of care, where the child or young person's underlying needs have not changed. As always, transparency of process, and involvement of the child or young person and their family, will be essential to maintain the fairness and consistency of the review.

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 the other service.

5. Transition

As far as possible, the aim of providing continuing care should be to support the move from dependence to independence, with children and young people being enabled to manage their condition themselves with a full understanding of the implications of their condition.

Every child or young person with a package of continuing care who is approaching adulthood should have a EHCP which reflects an active transition process to adult or universal services or to a more appropriate specialised or NHS Continuing Care pathway.

Once a young person reaches the age of 18, they are no longer eligible for continuing care for children, but may be eligible for NHS Continuing Healthcare, which is subject to legislation and specific guidance. It is important that young people and their families are helped to understand this and its implications right from the start of transition planning.

The Children's Complex Care Nurse should attend Halton's transition planning meeting, and share information regarding Children with Continuing Care needs with Adult service with parental consent.

It is best practice that future entitlement to adult NHS continuing healthcare should be clarified as early as possible in the transition planning process, especially if the young person's needs are likely to remain at a similar level until adulthood.

- At **14** years of age, the young person will be brought to the attention of adult continuing care services.
- At **16** years of age, children receiving continuing care will be referred to adult services and all screening for NHS continuing healthcare will be undertaken using the adult screening tool.
- At **17** years of age, an agreement in principle for adult NHS continuing healthcare should have been made, so that, wherever applicable, effective packages of care can be commissioned in time for the individual's 18th birthday (or later, if it is agreed that it is more appropriate for responsibility to be transferred then).
- At **18** years of age, full transition to adult NHS continuing healthcare or to universal and specialist services should have been made, except in instances where this is not appropriate.

If a young person who receives children's continuing care has been determined by the relevant CCG not to be eligible for a package of adult NHS continuing healthcare in respect of when they reach the age of 18, they should be advised of their non-eligibility and of their right to request an independent review, on the same basis as NHS continuing healthcare eligibility decisions regarding adults. The CCG should continue to participate in the transition process, in order to ensure an appropriate transfer of responsibilities, including consideration of whether they should be commissioning, funding or providing services towards a joint package of care (for example, to deliver an EHC plan).

Children and young people eligible for continuing care who have a personal health budget may not be eligible for NHS Continuing Healthcare when they reach 18. Although these young people will cease to have a "right to have" a personal health budget, CCGs can continue to offer services via a personal health budget on a discretionary basis, to support the transition to adult services. Transition should be

planned and agreed with the young person and their family or carers in good time to avoid any disruption or delay to implementing a package of care.

Even if a young person is not entitled to adult NHS continuing healthcare, they may have certain health needs that are the responsibility of the NHS. In such circumstances, CCGs should continue to play a full role in transition planning for the young person, and should ensure that appropriate arrangements are in place for services that meet these needs to be commissioned or provided. The focus should always be on the individual's desired outcomes and the support needed to achieve these.

A key aim is to ensure that a consistent package of support is provided during the years before and after the transition to adulthood. The nature of the package may change because the young person's needs or circumstances change. However, it should not change simply because of the move from children's to adult services or because of a change in the organisation with commissioning or funding responsibilities. Where change is necessary, it should be carried out in a planned manner, in full consultation with the young person. No services or funding should be unilaterally withdrawn unless a full joint health and social care assessment has been carried out and alternative funding arrangements have been put in place.

The legal responsibilities for child and adult services overlap in certain circumstances. In developing individual transition plans, partners should be clear where such overlaps occur, and the plans should clearly set out who will take responsibility and why. Some local health services for children and young people are only offered up to an age short of adulthood (i.e. 16).

It should be noted that regulations state that, in certain circumstances, when a young person in receipt of children's continuing care reaches adulthood, the care arrangements should be treated as having been made under the adult continuing care provisions. Guidance on the regulations sets out that young people approaching their 18th birthday will require a reassessment of their health and social care needs as part of their transition planning, and that, wherever possible, these young people should continue to receive their healthcare on an unchanged basis until they have been reassessed.

The Children's Complex Care Nurse, the LA lead and the Complex Needs Panel should monitor and actively participate in the reviews of those recipients of continuing care who are approaching adulthood.

The regulations and guidance for NHS Continuing Healthcare can be found at:

<https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care>

6. **The Complex Care Panel** should:

- Be independent from those involved in assessment;
- Be made up of key health commissioner and local authority professionals, including commissioners and clinical advisers;

- Consider the expressed wishes of the child or young person and their family and the care options that meet the assessed needs of the child or young person and their family;
- Take into account local authority children's and young people's services' requirements.
- Be allocated dedicated time to support this process.

7. Funding of Continuing Care

When a child or young person is assessed as needing a package of Continuing Care (ie DST thresholds are met), NHS HCCG and HBC have an agreement that all Continuing Care packages are funded by a 50:50 split where provision is not available through existing commissioned services.

Those children and young people who are eligible for Continuing Care but whose families have opted for a Direct Payment under Local Authority Direct Payments policy, will also be funded 50:50 by both the NHS HCCG and HBC.

Health consumables will be funded solely by NHS HCCG.

HBC will ensure that all contracts are distributed to the NHS HCCG. Before the contract is signed at the IPA stage the CC Coordinator will agree it and sign it off.

As the new SEND arrangements extend up to age 25, there will be young people aged 18-25, who are assessed as having a primary health need under the NHS Continuing Healthcare framework. This means that the NHS is responsible for providing all of the individual's assessed health and social care needs – including accommodation, if that is part of the overall need. The local authority may not have any responsibility towards the young person. The local authority would still take the lead in co-ordinating the EHC plan but the services they were ultimately responsible for securing would be negligible.

8. Personal health budgets

Under the *National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) (Amendment) Regulations 2013*, the families of a child or young person eligible for continuing care have a 'right to have' a personal health budget, covering the part of their care package which would be provided by the NHS.

Where a child or young person (or their family) eligible for continuing care requests a personal health budget, the responsible NHS HCCG must arrange for the provision of the care by means of a personal health budget.

Which will be achieved in one of several ways:

- a **direct payment** made to the young person or their family, through HBC;
- the agreement of a **notional budget** to be spent by the NHS HCCG following discussions with the child or young person, and their family (or other representative) as to how best to secure the provision they need;

- the transfer of a **real budget** agreed as above, to a person or organisation which applies the money in a way agreed between the NHS HCCG and the child or young person, and their family (or other representative).

NHS HCCGs publicise and promote the availability of personal health budgets to children and young people eligible for continuing care, on Halton Local Offer.

Personal health budgets are not restricted to children and young people eligible for continuing care. They can be offered to other children on a discretionary basis.

For more guidance on personal health budgets, see *Guidance on the “right to have” a Personal Health Budget in Adult NHS Continuing Healthcare and Children and Young People’s Continuing Care* (September 2014).

http://www.personalhealthbudgets.england.nhs.uk/library/Resources/Personalhealthbudgets/2014/Personal_health_budgets_right_to_have_guidance.pdf

9. Safeguarding

The assessment of children and young people for continuing care must 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 Local Authority Professional and the Nominated Health assessor 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 professional will give the child’s view.

The assessment of children and young people for continuing care must account of safeguarding policies and legislation, which place a duty on all agencies to safeguard and promote the welfare of children and young people.

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.

References

Department of Health (2016) "National Framework for Children and Young People's Continuing Care."

Department of Health (2012) "National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care"

Halton Borough Council, NHS Halton Clinical Commissioning Group (2016) "Children's & Young People's (0-25) Personalisation & Personal Budgets Policy (*including Personal Health Budgets and Direct Payments*) Special Educational Needs and Disability (SEND)" <http://localoffer.haltonchildrenstrust.co.uk/wp-content/uploads/2016/06/Personal-budgets-Policy-2016.pdf>

NHS England (2014) "Guidance on the "Right to Have" a Personal Health Budget in Adult Continuing Health Care and Children and Young People's Continuing Care"

Appendix 1

Referral Form

For Consideration of Eligibility for Continuing Care

<i>Please note, there must be multiagency consensus that the Child / Young Person has potential Continuing Care Needs prior to a referral being made</i>	
Name	
Date of Birth & Age at time of referral	
Date of referral	
Diagnosis <i>(please discuss specifically the Child/Young Person's needs which indicate eligibility for Continuing Care – please refer to the applicable Care Domains in Appendix 4)</i>	
Reason for referral:	
<ul style="list-style-type: none"> • To assess eligibility for continuing care (health contribution to package of support) 	
Support currently being accessed: <i>(Please evidence that all appropriate support is being accessed from universal and specialist services prior to this referral being made, e.g,CAMHS, Therapy services, Hospice or Targeted Short Break services)</i>	
Perceived unmet need / Gap(s) in existing service provision:	

Please enter contact details of Family, GP and other key professionals involved in the management of the child/young person below;

			For completion by Alison Sutch	
Name and Title / Relationship to Child / Young Person	Address, Telephone and email (Please note, referral cannot progress without these details)	In Support of referral (Please tick)	Date information requested	Date information received
Parents/ Guardians				
GP				
Community Paediatrician				
Lead Consultant (please state speciality)				
Other Consultant (please state speciality)				
Specialist Nurse				
Social Worker				
Lead Education Worker (e.g, SENCO)				
School Nurse				
Occupational Therapist				
Dietician				
SALT				
Physiotherapist				
Named Contact for Care Agency / Service Provider (if applicable)				
Other				

REFERRER	
Name	
Title	
Organisation	
Address	
Email	
Contact Number	

	<i>Delete as appropriate</i>
Completed consent form attached:	Yes / No
Multiagency needs assessment form attached:	Yes / No

Please note, this referral cannot progress without all requested attachments

Please password protect and email to Children's Complex Care Nurse, NHS Halton CCG at continuinghealthcare@halton.gov.uk

Appendix 2

Consent Form

Child / Young Person / Parental Agreement to Application for Consideration of Eligibility for Continuing Care

Halton Clinical Commissioning Group is responsible for co-ordinating the Children's Continuing Care process for individuals registered with a Halton GP.

In order to progress the application for consideration for Continuing Care it will be necessary to obtain information from all professionals and organisations involved in the care of the child and young person.

The information held by Halton Clinical Commissioning Group is held in the strictest confidence and we are obliged by law to adhere to strict controls regarding holding and using information.

Our commitment to you:

- To assess your case in line with the National Framework for Children and Young People's Continuing Care (2016 *revised*).
- To manage your personal information in line with current legislation and guidance.
- To ensure you are provided with support through care package management and reviews.
- To work with you to resolve disputes through the appeals and resolutions process.

If you have any questions about the above, please call us Monday to Friday, 9am to 5pm on: **0151 290 1976**.

Section 1: Consent Given by the Child/ Young Person with Capacity

Where a young person is aged over 16 years but **unable** to consent to the Continuing Care process themselves please go to Section 2

Where a child/young person is aged under 16 years please go to Section 3

I consent to being considered for the Children's Continuing Care process. I am signing to say I have read and understood the information given on page 1 of this document.

Please indicate below if there is any health, education and social care information you do not wish us to access or to share:

Name of Young Person:	
Young Person's Signature:	
Date:	

Professional Only

If the young person, aged over 16 years, has capacity but is unable to read or write: If the young person can indicate their consent by making their mark (on the consent form above) this should be encouraged.

Where the young person has capacity but is only able to verbally consent, this must be witnessed by two people:

Signature:	Name:	Designation / relationship:	Date:

Section 2: For Young People aged over 16 years where it is felt they are Unable to Consent to the Children’s Continuing Care Process

This section must be completed by the **professional** completing the checklist / DST. All parts of this section must be completed for the application to be accepted.

2a Assessment of Capacity – as per the Mental Capacity Act 2005

Does the young person have a temporary or permanent impairment or a disturbance in the functioning of the mind or brain?

YES / NO (Give reasons):

If ‘Yes’ are they able to understand, retain and weigh up the information and communicate their decision?

YES / NO (Give reasons):

If ‘No’ they will lack capacity

I have considered whether the young person is likely to regain capacity.

If **YES**, can the decision wait until then?

If **NO**, is the young person likely to regain capacity?

If **YES**, can the decision wait until then?

If NO, continue with the Best Interest Decision

2b Best Interest Decision			
<p>Where possible and appropriate have you consulted with other professionals, relevant documentation (e.g. GP notes, care plans, nursing notes) and those close to the young person? YES / NO</p> <p>Do you believe this process to be in the young person's best interest? YES / NO (Give reasons):</p>			
2c Involvement from family and/or advocate including IMCA (if appropriate)			
<p>It is good practice to consult with those close to the person (e.g. family or advocate) unless you have good reason to believe that the young person would not have wished for particular individuals to be consulted, or unless the urgency of their situation prevents this.</p>			
<p>I confirm I have been involved in the discussion with the relevant professional over the capacity assessment of:</p> <p>I understand that they are unable to give their consent. I also understand the assessment can lawfully be provided if it is in their best interest.</p>			
Name:	Signature	Relationship to person being assessed:	Date:
<p>If you have not liaised with family or an advocate please state why:</p> <p>2d Signature of Health or Social Care Professional</p> <p>The above process is, in my professional judgement, in the best interests of the young person, who lacks capacity to consent for him/herself. Where possible and appropriate I have discussed the young person's condition with those close to him/her and taken their knowledge of the young person's views and beliefs into account in determining his/her best interests.</p> <p>I have/have not sought a second opinion</p>			
Name:	Signature:	Designation:	Date:
Where second opinion sought, s/he should sign below to confirm agreement:			
Name:	Signature:	Designation:	Date:

Section 3: For those aged under 16 years, Consent Given by the Person with Parental Responsibility for the Child	
I consent to the named child being considered for the Children's Continuing Care process. I am signing to say I have read and understood the information given on page 1 of this document.	
Please indicate below if there is any health, education and social care information you do not wish us to access or to share:	
Name:	
Relationship to Child/Young Person:	
Signature:	
Date:	

Appendix 3

Continuing Care Pre-assessment Checklist

This form must have input from a Health Professional in conjunction with other appropriate professionals involved with the child and should be completed prior to referral for full Continuing Care Assessment.

Name:	
DOB:	
NHS Number:	

Primary health need / diagnosis:

Care Domain	N	L	M	H	S	P	Supporting Rationale
Breathing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Eating and Drinking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Mobility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Continence & Elimination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Skin and Tissue Viability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		

Communication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
Drug Therapies and Medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Psychological and Emotional	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
Seizures	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Challenging Behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Score							

gh' ratings, 1 'severe' rating or 1 'priority' rating is likely to indicate Continuing Care needs.

- If likely continuing care needs are indicated or borderline, this should be a trigger for full health assessment to establish eligibility; consent should be obtained and referral made to continuinghealthcare@halton.gov.uk
- If referral for full assessment is not considered appropriate, then the child/young person's needs should be met through a case management approach.

Summary of identified needs:

What services are currently being accessed?

Which professionals are currently involved and who is contributing what?

Area of 'unmet' need and recommendation for support:

(If a referral for full assessment is to be made, please explain why existing resources at universal, specialist and targeted level cannot meet this need)

Pre-assessment checklist completed by:

Name:	
Title:	
Date:	

Others who contributed to the checklist:

Name:	Title:

Appendix 4

Decision Support Tool for Children and Young People's Continuing Care

Date assessment completed:	
Health Professional responsible for completing this form (This is usually the same person who completed the screening checklist)	Name: Title: Organization: Address: Email: Telephone: Mobile:
Lead Professional / Referrer	Name: Title: Organisation: Address: Email: Telephone: Mobile:
GP	Name: Address: Telephone:
Person / those with Parental Responsibility:	Name: Address: Telephone:

1 Others who contributed to the Assessment

Name: Title: Organisation: Address: Email: Telephone: Mobile:	Name: Title: Organisation: Address: Email: Telephone: Mobile:
Name: Title: Organisation: Address: Email: Telephone: Mobile:	Name: Title: Organisation: Address: Email: Telephone: Mobile:

Name: Title: Organisation: Address: Email: Telephone: Mobile:	Name: Title: Organisation: Address: Email: Telephone: Mobile:
Name: Title: Organisation: Address: Email: Telephone: Mobile:	Name: Title: Organisation: Address: Email: Telephone: Mobile:

Supporting Information Referred to within the Assessment (Please attach)

Evidence	Author & Title	Date

Child's diagnosis / ongoing conditions

Current Package

Reason for application to Complex Needs Panel

Relevant updates since last presented at panel

Children's decision support tool

Outcomes

1. The assessment of a child's continuing care needs must consider the outcomes necessary to enable the child or young person to get the best from life, and outcomes relating to transition (where the child is 14 years or older), identifying unmet need.
2. They should be specific, deliverable and linked directly to the child's wishes. They should include where appropriate, outcomes for transition, through key changes in a child or young person's life, such as changing schools, moving from children's to adult care and/or from paediatric services to adult health, or moving on from further education to adulthood.
3. Key issues would include:
 - Maintaining a safe environment.
 - Communicating.
 - Breathing.
 - Eating and drinking.
 - Elimination.
 - Personal cleaning and dressing.
 - Controlling body temperature.
 - Mobilising.
 - Playing.
 - Learning.
 - Expressing individuality.
 - Sleeping.
 - Employment
 - Independence
 - Further education
 - End of life.
 - Pain management

Care domains

4. Health assessors should consider the needs of the child or young person across the following 11 domains of care. Care has been taken to avoid duplicating needs in two separate domains. However, assessors should consider how different but inter-related needs across more than one domain can complicate the child or young person's overall care needs and result in sufficient complexity, intensity or risk to demonstrate continuing care needs. Examples of this might include the relationship between skin integrity and continence, or cognitive impairment and behaviour and/or communication.
5. It is essential that clear evidence is obtained to support assessments in the relevant domains, and that this evidence is recorded as part of the continuing care assessment, and included in any subsequent care plan.
6. As a rule of thumb, a child is likely to have continuing care needs if assessed as having a severe or priority level of need in at least one domain of care, or a high level of need in at least three domains of care.
7. The level of need in a single domain may not on its own indicate that a child or young person has a continuing care need, but will contribute to a picture of overall care needs across all domains. Levels of need are relative to each other as well as to those in other care domains. It is not possible to equate a number of incidences of one level with a number of incidences of another level – that needs assessed as 'moderate' in two domains are the equivalent of one 'high' level of need, for example. In presenting recommendations and costed options to a multi-agency forum, nominated children and young people's health assessors should consider the level of need identified in **all** care domains in order to gain the overall picture.
8. These guidelines should not be used in a restrictive way. Nominated children and young people's health assessors should be mindful that even if the child or young person is assessed as not having continuing care needs, they may require other healthcare input from universal services or community children/young person's nursing or other specialist services.

Breathing

Describe the child or young person's specific needs relevant to this domain.

- 1. Describe below the actual needs of the individual, providing the evidence that informs the decision below on which level is appropriate, including the frequency and intensity of need, unpredictability, deterioration and any instability.**
- 2. Note any overlap with other domains.**
- 3. Describe the impact on the family**

Breathing - assessors should indicate the level of need

Description	Level of need
Breathing typical for age and development.	No additional needs
Routine use of inhalers, nebulisers, etc.; or care plan or management plan in place to reduce the risk of aspiration.	Low
Episodes of acute breathlessness, which do not respond to self-management and need specialist-recommended input; or intermittent or continuous low-level oxygen therapy is needed to prevent secondary health issues; or supportive but not dependent non-invasive ventilation which may include oxygen therapy which does not cause life-threatening difficulties if disconnected; or child or young person has profoundly reduced mobility or other conditions which lead to increased susceptibility to chest infection (Gastroesophageal Reflux Disease and Dysphagia); or requires daily physiotherapy to maintain optimal respiratory function; or requires oral suction (at least weekly) due to the risk of aspiration and breathing difficulties; or has a history within the last three to six months of recurring aspiration/chest infections.	Moderate
Requires high flow air / oxygen to maintain respiratory function overnight or for the majority of the day and night; or is able to breath unaided during the day but needs to go onto a ventilator for supportive ventilation. The ventilation can be discontinued for up to 24 hours without clinical harm; or requires continuous high level oxygen dependency, determined by clinical need; or has a need for daily oral pharyngeal and/or nasopharyngeal suction with a management plan undertaken by a specialist practitioner; or stable tracheostomy that can be managed by the child or young person or only requires minimal and predictable suction / care from a carer.	High
Has frequent, hard-to-predict apnoea (not related to seizures); or severe, life-threatening breathing difficulties, which require essential oral pharyngeal and/or nasopharyngeal suction, day or night; or a tracheostomy tube that requires frequent essential interventions (additional to routine care) by a fully trained carer, to maintain an airway; or	Severe

<p>requires ventilation at night for very poor respiratory function; has respiratory drive and would survive accidental disconnection, but would be unwell and may require hospital support.</p>	
<p>Unable to breath independently and requires permanent mechanical ventilation; or has no respiratory drive when asleep or unconscious and requires ventilation, disconnection of which could be fatal; or a highly unstable tracheostomy, frequent occlusions and difficult to change tubes.</p>	<p>Priority</p>

Eating and Drinking

Describe the child or young person's specific needs relevant to this domain.

1. Describe the actual needs of the individual, providing the evidence that informs the decision below on which level is appropriate, including the frequency and intensity of need, unpredictability, deterioration and any instability.
2. Note any overlap with other domains.
3. Describe the impact on the family

Eating and drinking – assessors should indicate the level of need

Description	Level of need
<p>Able to take adequate food and drink by mouth, to meet all nutritional requirements, typical of age.</p>	<p>No additional needs</p>
<p>Some assistance required above what is typical for their age; or needs supervision, prompting and encouragement with food and drinks above the typical requirement for their age; or needs support and advice about diet because the underlying condition gives greater chance of non-compliance, including limited understanding of the consequences of food or drink intake; or needs feeding when this is not typical for age, but is not time consuming or not unsafe if general guidance is adhered to.</p>	<p>Low</p>
<p>Needs feeding to ensure safe and adequate intake of food; feeding (including liquidised feed) is lengthy; specialised feeding plan developed by speech and language therapist; or unable to take sufficient food and drink by mouth, with most nutritional requirements taken by artificial means, for example, via a non-problematic tube feeding device, including nasogastric tubes.</p>	<p>Moderate</p>
<p>Faltering growth, despite following specialised feeding plan by a speech and language therapist and/or dietician to manage nutritional status,. or dysphagia, requiring a specialised management plan developed by the speech and language therapist and multi-disciplinary team, with additional skilled intervention to ensure adequate nutrition or hydration and to minimise the risk of choking, aspiration and to maintain a clear airway (for example through suction); or problems with intake of food and drink (which could include vomiting), requiring skilled intervention to manage nutritional status; weaning from tube feeding dependency and / recognised eating disorder, with self-imposed dietary regime or self-neglect, for example, anxiety and/or depression leading to intake problems placing the child/young person at risk and needing skilled intervention; or problems relating to a feeding device (e.g. nasogastric tube) which require a risk-assessment and management plan undertaken by a speech and language therapist and multidisciplinary team and requiring regular review and reassessment. Despite the plan, there remains a risk of choking and/or aspiration.</p>	<p>High</p>
<p>The majority of fluids and nutritional requirements are routinely taken by intravenous means.</p>	<p>Severe</p>

Mobility

Describe the child or young person's specific needs relevant to this domain.

- 1. Describe the actual needs of the individual, providing the evidence that informs the decision below on which level is appropriate, with reference to movement and handling where relevant. Describe the frequency and intensity of need, unpredictability, deterioration and any instability.**
- 2. Note any overlap with other domains.**
- 3. Describe the impact on the family**

Mobility - assessors should indicate the level of need

Description	Level of need
Mobility typical for age and development.	No additional needs
<p>Able to stand, bear their weight and move with some assistance, and mobility aids.</p> <p>or</p> <p>moves with difficulty (e.g. unsteady, ataxic); irregular gait.</p>	Low
<p>Difficulties in standing or moving even with aids, although some mobility with assistance.</p> <p>or</p> <p>sleep deprivation (as opposed to wakefulness) due to underlying medical related need (such as muscle spasms, dystonia), occurring three times a night, several nights per week;</p> <p>or</p> <p>unable to move in a way typical for age; cared for in single position, or a limited number of positions (e.g. bed, supportive chair) due to the risk of physical harm, loss of muscle tone, tissue viability, or pain on movement, but is able to assist.</p>	Moderate
<p>Unable to move in a way typical for age; cared for in single position, or a limited number of positions (e.g. bed, supportive chair) due to the risk of physical harm, loss of muscle tone, tissue viability, or pain on movement; needs careful positioning and is unable to assist or needs more than one carer to reposition or transfer;</p> <p>or</p> <p>at a high risk of fracture due to poor bone density, requiring a structured management plan to minimise risk, appropriate to stage of development;</p> <p>or</p> <p>involuntary spasms placing themselves and carers at risk;</p> <p>or</p> <p>extensive sleep deprivation due to underlying medical/mobility related needs, occurring every one to two hours (and at least four nights a week).</p>	High
<p>Completely immobile and with an unstable clinical condition such that on movement or transfer there is a high risk of serious physical harm;</p> <p>or</p> <p>positioning is critical to physiological functioning or life.</p>	Severe

Continence or elimination

Describe the child or young person's specific needs relevant to this domain.

- a. Describe the actual needs of the individual, providing the evidence that informs the decision below on which level is appropriate, including the frequency and intensity of need, unpredictability, deterioration and any instability.**
- b. Take into account any aspect of continence care associated with behaviour in the Behaviour domain.**
- c. Describe the impact on the family**

Continence or elimination - assessors should indicate the level of need

Description	Level of need
Continence care is routine and typical of age.	No additional needs
Incontinent of urine but managed by other means, for example, medication, regular toileting, pads, use of penile sheaths; or is usually able to maintain control over bowel movements but may have occasional faecal incontinence.	Low
Has a stoma requiring routine attention, or doubly incontinent but care is routine; or self-catheterisation; or difficulties in toileting due to constipation, or irritable bowel syndrome; requires encouragement and support.	Moderate
Continence care is problematic and requires timely intervention by a skilled practitioner or trained carer; or intermittent catheterisation by a trained carer or care worker; or has a stoma that needs extensive attention every day. or requires haemodialysis in hospital to sustain life.	High
Requires dialysis in the home to sustain life.	Severe

Skin and tissue viability

Interpretation point: where a child or young person has a stoma, only the management of the stoma itself as an opening in the tissue should be considered here (i.e. a tracheostomy should only be considered here where there are issues relating to the opening; the use of the tracheostomy to aid breathing, and its management should be considered under **Breathing**.)

Describe the child or young person's specific needs relevant to this domain.

1. Describe the actual needs of the individual, providing the evidence that informs the decision below on which level is appropriate, including the frequency and intensity of need, unpredictability, deterioration and any instability.
2. Note any overlap with other domains.
3. Describe the impact on the family

Skin and tissue viability - assessors should indicate the level of need

Description	Level of need
No evidence of pressure damage or a condition affecting the skin.	No additional needs
Evidence of pressure damage or a minor wound requiring treatment; or skin condition that requires clinical reassessment less than weekly; or well established stoma which requires routine care; or has a tissue viability plan which requires regular review.	Low
Open wound(s), which is (are) responding to treatment; or active skin condition requiring a minimum of weekly reassessment and which is responding to treatment; or high risk of skin breakdown that requires preventative intervention from a skilled carer several times a day, without which skin integrity would break down; or high risk of tissue breakdown because of a stoma (e.g. gastrostomy, tracheostomy, or colostomy stomas) which require skilled care to maintain skin integrity.	Moderate
Open wound(s), which is (are) not responding to treatment and require a minimum of daily monitoring/reassessment; or active long-term skin condition, which requires a minimum of daily monitoring or reassessment; or specialist dressing regime, several times weekly, which is responding to treatment and requires regular supervision.	High
Life-threatening skin conditions or burns requiring complex, painful dressing routines over a prolonged period.	Severe

Communication

Describe the child or young person's specific needs relevant to this domain.

- 1. Describe the actual needs of the individual, providing the evidence that informs the decision below on which level is appropriate, including the frequency and intensity of need, unpredictability, deterioration and any instability.**
- 2. Note any overlap with other domains.**
- 3. Describe the impact on the family**

Communication - assessors should indicate the level of need

Description	Level of need
<p>Able to understand or communicate clearly, verbally or non-verbally, within their primary language, appropriate to their developmental level. The child/young person's ability to understand or communicate is appropriate for their age and developmental level within their first language.</p>	<p>No additional needs</p>
<p>Needs prompting or assistance to communicate their needs. Special effort may be needed to ensure accurate interpretation of needs, or may need additional support visually – either through touch or with hearing.</p> <p>Family/carers may be able to anticipate needs through non-verbal signs due to familiarity with the individual.</p>	<p>Low</p>
<p>Communication of emotions and fundamental needs is difficult to understand or interpret, even when prompted, unless with familiar people, and requires regular support. Family/carers may be able to anticipate and interpret the child/ young person's needs due to familiarity.</p> <p>or support is always required to facilitate communication, for example, the use of choice boards, signing and communication aids.</p> <p>or ability to communicate basic needs is variable depending on fluctuating mood; the child/young person demonstrates severe frustration about their communication, for example, through withdrawal.</p>	<p>Moderate</p>
<p>Even with frequent or significant support from family/carers and professionals, the child or young person is rarely able to communicate basic needs, requirements or ideas.</p>	<p>High</p>

Drug therapies and medication

Describe the child or young person's specific needs relevant to this domain.

- 1. Describe below the actual needs of the individual and provide the evidence that informs the decision below on which level is appropriate, including the frequency and intensity of need, unpredictability, deterioration and any instability.**
- 2. Note any overlap with other domains**
- 3. Describe the impact on the family**

Drug therapies and medication – assessors should indicate the level of need

Description	Level of need
Medicine administered by parent, carer, or self, as appropriate for age.	No additional needs
<p>Requires a suitably trained family member, formal carer, teaching assistant, nurse or appropriately trained other to administer medicine due to</p> <ul style="list-style-type: none"> • age • non-compliance • type of medicine; • route of medicine; and/or • site of medication administration 	Low
<p>Requires administration of medicine regime by a registered nurse, formal employed carer, teaching assistant or family member specifically trained for this task, or appropriately trained others;</p> <p>or</p> <p>monitoring because of potential fluctuation of the medical condition that can be non-problematic to manage;</p> <p>or</p> <p>sleep deprivation due to essential medication management – occurring more than once a night (and at least twice a week).</p>	Moderate
<p>Drug regime requires management by a registered nurse at least weekly, due to a fluctuating and/or unstable condition;</p> <p>or</p> <p>sleep deprivation caused by severe distress due to pain requiring medication management – occurring four times a night (and four times a week).</p> <p>or</p> <p>requires monitoring and intervention for autonomic storming episodes.</p>	High
<p>Has a medicine regime that requires daily management by a registered nurse and reference to a medical practitioner to ensure effective symptom management associated with a rapidly changing/deteriorating condition;</p> <p>or</p> <p>extensive sleep deprivation caused by severe intractable pain requiring essential pain medication management – occurring every one to two hours</p> <p>or</p> <p>requires continuous intravenous medication, which if stopped would be life threatening (e.g. epoprostenol infusion).</p>	Severe
<p>Has a medicine regime that requires at least daily management by a registered nurse and reference to a medical practitioner to ensure effective symptom and pain management associated with a rapidly changing/deteriorating condition, where one-to-one monitoring of symptoms and their management is essential.</p>	Priority

Psychological and emotional needs (beyond what would typically be expected from a child or young person of their age)

Describe the child or young person's specific needs relevant to this domain.

- 1. Describe the actual needs of the child / young person, providing the evidence that informs the decision below on which level is appropriate, including the frequency and intensity of need, unpredictability, deterioration and any instability.**
- 2. Note any overlap with other domains.**
- 3. Describe the impact on the family**

Psychological and emotional needs (beyond what would typically be expected from a child or young person of their age) – assessors should indicate the level of need

Interpretation point: a separate domain considers **Challenging Behaviour**, and assessors should avoid double counting the same need.

Description	Level of need
Psychological or emotional needs are apparent but typical of age and similar to those of peer group.	No additional needs
Periods of emotional distress (anxiety, mildly lowered mood) not dissimilar to those typical of age and peer group, which subside and are self-regulated by the child/young person, with prompts/ reassurance from peers, family members, carers and/or staff within the workforce.	Low
Requires prompts or significant support to remain within existing infrastructure; periods of variable attendance in school/college; noticeably fluctuating levels of concentration. Self-care is notably lacking (and falls outside of cultural/peer group norms and trends), which may demand prolonged intervention from additional key staff; self-harm, but not generally high risk;	Moderate
Evidence of low moods, depression, anxiety or periods of distress; reduced social functioning and increasingly solitary, with a marked withdrawal from social situations; limited response to prompts to remain within existing infrastructure (marked deterioration in attendance/attainment / deterioration in self-care outside of cultural/peer group norms and trends).	High
<p>Rapidly fluctuating moods of depression, necessitating specialist support and intervention, which have a severe impact on the child/young person's health and well-being to such an extent that the individual cannot engage with daily activities such as eating, drinking, sleeping or which place the individual or others at risk;</p> <p>or</p> <p>acute and/or prolonged presentation of emotional/psychological deregulation, poor impulse control placing the young person or others at serious risk, and/or symptoms of serious mental illness that places the individual or others at risk; this will include high-risk, self-harm.</p>	Severe

Seizures

Describe the child or young person's specific needs relevant to this domain.

- 1. Describe below the actual needs of the individual providing the evidence that informs the decision below on which level is appropriate (referring to appropriate risk assessments), including the frequency and intensity of need, unpredictability, deterioration and any instability.**
- 2. Note any overlap with other domains.**
- 3. Describe the impact on the family**

Seizures – assessors should indicate the level of need

Description	Level of need
No evidence of seizures.	No additional needs
History of seizures but none in the last three months; medication (if any) is stable; or occasional absent seizures and there is a low risk of harm.	Low
Occasional seizures including absences that have occurred with the last three months which require the supervision of a carer to minimise the risk of harm; or up to three tonic-clonic seizures every night requiring regular supervision.	Moderate
Tonic-clonic seizures requiring rescue medication on a weekly basis; or 4 or more tonic-clonic seizures at night.	High
Severe uncontrolled seizures, occurring at least daily. Seizures often do not respond to rescue medication and the child or young person needs hospital treatment on a regular basis. This results in a high probability of risk to his/her self.	Severe

Challenging behaviour

Describe the child or young person's specific needs relevant to this domain.

- 1. Describe the actual needs of the individual, including any episodic needs. Provide the evidence that informs the decision below on which level is appropriate, such as the times and situations when the behaviour is likely to be performed across a range of typical daily routines and the nature, intensity, unpredictability, frequency, severity and duration of the behaviour.**
- 2. Note any overlap with other domains.**
- 3. Describe the impact on the family**

Challenging behaviour – assessors should indicate the level of need

Description	Level of need
No incidents of behaviour which challenge parents/carers/staff.	No additional needs
Some incidents of behaviour which challenge parents/carers/staff but which do not exceed expected behaviours for age or stage of development and which can be managed within mainstream services (e.g. early years support, health visiting, school).	Low
Occasional challenging behaviours which are more frequent, more intense or more unusual than those expected for age or stage of development, which are having a negative impact on the child and their family / everyday life.	Moderate
Regular challenging behaviours such as aggression (e.g. hitting, kicking, biting, hair-pulling), destruction (e.g. ripping clothes, breaking windows, throwing objects), self-injury (e.g. head banging, self-biting, skin picking), or other behaviours (e.g. running away, eating inedible objects), despite specialist health intervention and which have a negative impact on on the child and their family / everyday life.	High
Frequent, intense behaviours such as aggression, destruction, self-injury, despite intense multi-agency support, which have a profoundly negative impact on quality of life for the child and their family, and risk exclusion from the home or school.	Severe
Challenging behaviours of high frequency and intensity, despite intense multi-agency support, which threaten the immediate safety of the child or those around them and restrict every day activities (e.g. exclusion from school or home environment).	Priority

Decision Support Tool for Children and Young People’s Continuing Care
Assessed Levels of Need

Care Domain	P	S	H	M	L	N
Breathing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Eating and drinking		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mobility		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Continence or elimination		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skin and tissue viability		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Communication			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drug Therapies and Medicines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychological and emotional needs			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Seizures		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Challenging behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Totals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<p>Three ‘high’ ratings, one ‘severe’ rating or one ‘priority’ rating is likely to indicate continuing care needs.</p>						

ELIGIBILITY

Decision	
Name	
Designation:	
Date:	

<p>Authorised by Individual Commissioning Manager for Children’s Complex Care</p>	
Date:	
Name / Signature:	

Appendix 6

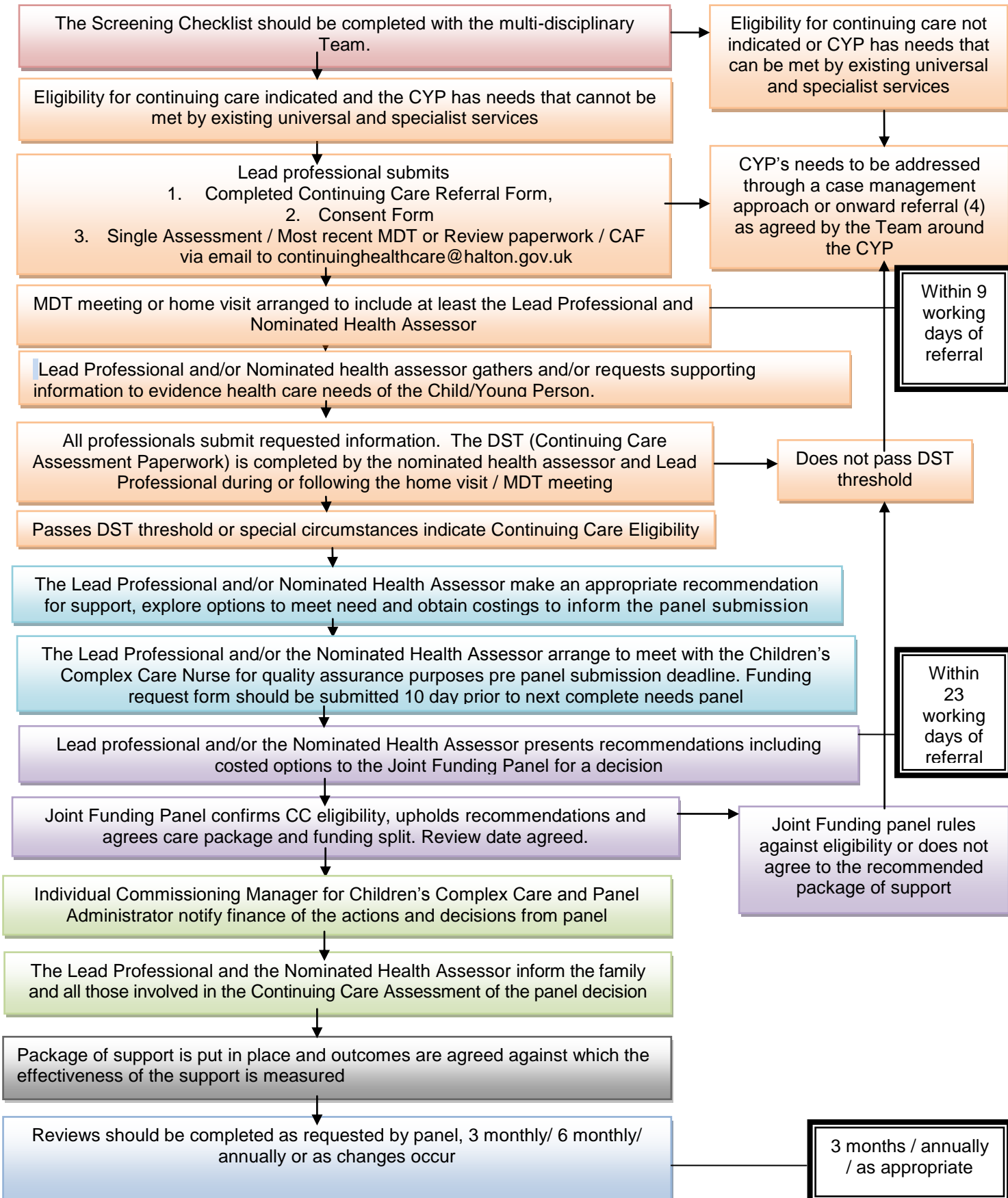
CHC ELIGIBILITY QUALITY ASSURANCE FORM		Name:	
Case Type:	<i>New CHC referral</i>	DOB:	
	<i>CC review</i>	CareFirst Ref no.	
Address:		Current Location:	
NOK / representative details:		Present at Assessment?	
		Date of Referral	
		Date of MDT	
Date of Checklist /Previous DST		Assessment/Review date:	
Date of Current DST		Date HCCG QA:	
Information leaflet shared		Personal Budget Discussed	
MDT Members/Referrer:	Lead Health Professional		
	Social Worker		
	Other		
Clinical summary / identified risks:			
Other relevant information:	Recommended care package:		
Fast Track Application	Date Received:	Date Agreed:	
	Supporting Documentation:	Date:	Satisfactory/ additional information requested
Consent for assessment			
Nursing			
Social Worker			
Therapist			
Medical Report			
Psychology Report			
Other			
Risk assessments			
EHCP			
Nursing Care Plan			

<u>Domain</u>	<u>Previous DST Level of need</u>	<u>DST Level of need</u>	<u>Comment</u>
Breathing			Information provided supports level of need.
Eating and drinking			Information provided supports level of need.
Mobility			Information provided supports level of need.
Continence or elimination			Information provided supports level of need.
Skin and tissue viability			Information provided supports level of need.
Communication			Information provided supports level of need.
Drug therapies and Medication			Information provided supports level of need.
Psychological and emotional needs			Information provided supports level of need.
Seizures			Information provided supports level of need.
Challenging behaviour			Information provided supports level of need.
MDT / Referrer Recommendation:	<p>The following four areas of assessment are important to determining the need for continuing care. The nominated children and young people's health assessor undertaking the assessment should demonstrate evidence based professional judgement in each of the four areas to support their recommendation(s).</p> <p>The Four Areas of Assessment</p> <ol style="list-style-type: none"> 1. The preferences of the child or young person and their family 2. Holistic assessment of the child or young person and their family, including carer assessment 3. Reports and risk assessments from the multidisciplinary team 4. The Children's Decision Support Tool <p><i>Individual Not considered eligible for CHC but eligible for Funded Nursing Care contribution / Joint care:</i></p> <p>Date Agreed:.....Signed..... </p>		

Reviews only:	<p>No change in presentation based on previous assessment of need: Outcome of Review:</p> <p>Individual remain Eligible for NHS Continuing health care and meets the criteria for Primary Health Need.</p> <p>Date Agreed.....Signed..... </p> <p>Individual Remains Eligible for Funded Nursing Care as identified within the Checklist:</p> <p>Date Agreed.....Signed..... </p>
Outcome:	<p>Agreed: HCCG Date.....</p> <p>Print Name.....</p> <p>Designation.....</p> <p>Agreed: HBC Date.....</p> <p>Print Name.....</p> <p>Designation</p>
HCCG QA comments:	
Review period:	3 month / 12 month
Name	
Designation	
Signature	
Date	

Appendix 5

Children and Young People's Continuing Care: Pathway



1. A child or young person may reach this stage in a variety of ways: through sudden unexpected need, through deterioration of a long-term condition or through congenital disease.
2. A lead professional is someone who takes the lead to co-ordinate provision and be a single point of contact for a child and their family, when a range of services are involved with the child or family and an integrated response is required. The lead professional is not a job title or a new role, but a set of functions to be carried out as part of the delivery of effective integrated support. The lead professional should be the professional most associated with the child/young person's predominant need.
3. A nominated health assessor is a health professional who is already part of the team around the Child/Young Person. The nominated health assessor works in conjunction with the lead professional to ensure accurate completion of the Continuing Care Assessment and to facilitate access to appropriate support.
4. Onward referral to:
 - a. Short break / Resource / Single agency panel
 - b. Relevant professional or service to meet identified need
5. Assessments, records or reports may include: Pen picture, Common Assessment Framework, single assessment (Social Worker's Report), carer's assessment, family/carer assessment plan, clinic letter, health summary, specialist's assessment, educational statement of Special Educational Needs, annual reviews and any other relevant review information, records and/or reports.

Glossary of Abbreviations	
CYP	Child / Young Person
CAF	Common Assessment Framework
MDT	Multi-Disciplinary Team
DST	Decision Support Tool
CC	Continuing Care

Who decides? What happens next?

The **health assessor** will make a case to a panel of experts, who decide based on the evidence, and the recommendation, if the child or young person has a continuing care need.

A decision is usually made 6-8 weeks from referral.

Depending on the decision, a package of care is then agreed; some of this care may be provided through existing services; some may need to be specially arranged.

The CCG will keep the package of care under regular review to ensure the developing child or young person's needs continue to be supported. A child or young person's eligibility for continuing care may change as their needs change.

Local Contact

Alison Sutch
Children's Complex Care Nurse
NHS Halton CCG
1st Floor
Runcorn Town Hall
Heath Road
Runcorn
WA7 5TD
Tel; 01928 593479/ 0151 511 8103
Mobile Number 07557848978



Department
of Health

Disabled and Ill Child Services Team
2E60, Department of
Health, Quarry House,
Quarry Hill, Leeds LS2 7UE



Department
of Health

Children and young people's continuing care

A brief guide for young
people and parents



January 2011

What is continuing care?

Some children and young people (up to age 18), may have very complex health needs.

These may be the result of:

- congenital conditions
- long-term or life-limiting conditions
- disability
- serious illness or injury

Children with such complex needs may need additional health support to that which is routinely available from GP practices, hospitals or in the community.

This additional package of care is called continuing care. The clinical commissioning group, which is responsible for arranging for health services locally, has responsibility for assessing children and young people to see if they need a package of continuing care.

Who is eligible?



Any child or young person up to their 18th birthday who has a complex health need may be eligible.

When a young person reaches 18, the adult NHS Continuing Healthcare arrangements apply.

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. The CCG will assess any young person in receipt of continuing care when they are aged 16-17, to see if they are likely to be eligible for NHS Continuing Healthcare when they turn 18.

How can we access continuing care?

A referral can be made by any health professional or carer who feels a continuing care package may be required.

When a child or young person is referred for an assessment, the CCG might first check if they are likely to need a full assessment.

A **health assessor** will then collect evidence of the child's needs, drawing on the advice of health and care professionals. A national framework provides guidance, and a set of categories of needs to support decisions on whether or not a child has a continuing care need.

An important part of the assessment is to capture the preferences of the child or young person and their family.

The assessment will look at the current care being provided but a decision on whether or not a child or young person has a continuing care need is based on the nature of their needs, rather than the care available, or whether or not they have a particular condition.

HALTON CYP COMPLEX NEEDS PANEL FUNDING REQUEST TEMPLATE

Name	
Date of Birth	
Address	
School	
Carer	
GP	
<p>Background This section must address the following;</p> <ul style="list-style-type: none"> • the child's diagnosis & description of needs, • current level of support, • siblings/family members • services provided • school progress 	
<p>Assessment of Need This section must address the following:</p> <ul style="list-style-type: none"> • The child's annual health assessment or most recent health assessment and the outcome, incl date • The child's annual SEN review, incl date • Details of the child and families unmet need and the evidence that supports it • Summary of most recent assessment, i.e. CAF.Core assessment. 	

<p>Current Plan CAF/CiN/CP/CiC/SEN <i>This section must include;</i></p> <ul style="list-style-type: none"> • <i>Dates of planning meetings and who attended</i> • <i>Clear summary of the current level of support including costings</i> • <i>Evidence of the role of the child's advocate</i> 	
<p>Recommendation <i>This section must address the following</i></p> <ul style="list-style-type: none"> • <i>How the recommendations will address the identified unmet need</i> • <i>Clear recommendation supported by evidence</i> 	
<p>Name & Title of Report Author.</p>	
<p>Date</p>	