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NHS
Black Country and West Birmingham
Clinical Commissioning Group

Dudley – Children's & Young Peoples Continuing Care Policy

Unique Identifier:	IA/XX/061/V1.2
Version:	1.2
Ratified by:	Individual Commissioning Assurance Committee
Date ratified:	At present the CCG is going through a harmonisation process so that we have a single set of Black Country and West Birmingham policies. Until then, each place will operate on the basis of their historic policies and there will be some differences.
Name of Originator/author/job title:	Kellie Lennon, Clinical Commissioning Manager, DIHC Neill Bucktin, Managing Director Dudley Place, BCWB CCG
Date Issued:	February 2021
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DOCUMENT STATUS

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AMENDMENT HISTORY

VERSION	DATE	AMENDMENT HISTORY
D7.0	October 2016	First Draft created
CD/XX/079/V1	December 2016	Formatted in to CCG Format and issues identifier
CD/XX/079/V1.1	April 2017	Addition of 13.2 and new RAT Tool incorporated
IA/XX/061/V1.2	February 2021	Dudley CCG policy rebranded to merged BCWB CCG branding. New identifier provided. Will be reviewed as part of harmonisation of BCWB Policies Process. No approval required at this stage.

REVIEWERS

This document has been reviewed by:

NAME	DATE	TITLE/RESPONSIBILITY	VERSION
Linda Cropper	Oct 16	Commissioning Manager	D7.0
Su Vincent	Oct 16	Designated Nurse for Safeguarding Children	D7.0
Tim Horsburgh	Oct 16	Clinical Lead for Paediatrics	D7.0
Kellie Lennon	Oct 16	Paediatric Continuing Care Coordinator	D7.0
Neill Bucktin	Oct 16	Director of Commissioning	D7.0
Emma Smith	Dec 16	Governance Support Manager	V1.0
Emma Smith	Apr 17	Governance Support Manager	V1.1
Kellie Lennon	Feb 21	Clinical Commissioning Manager: CYP with Complex Needs and DCO	V1.2

APPROVALS

This document has been approved by:

VERSION	NAME	DATE
V1.0	Commissioning Development Committee	16 November 2016
V1.1	Commissioning Development Committee	22 March 2017

N.B: the version of this policy posted on the intranet must be a PDF copy of the approved version.

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RELATED DOCUMENTS

These documents will provide additional information.

NAME OF DOCUMENT
Safeguarding Commissioning Policy
Safeguarding Adults Policy Link https://safeguarding.dudley.gov.uk/media/16598/dudley-adult-sfaeguarding-procedures-v11-19112020.pdf
Managing Safeguarding Allegations
Safeguarding Supervision – Child and Adult
Safeguarding Children Practice Policy 2018
Mental Capacity Act 2005, The Children Act 1989 & 2004
National Framework for Children and Young People's Continuing Care 2016
Children and Families Act 2014
Working Together to Safeguard Children 2018
Children and Social Work Act 2017 Link www.legislation.gov.uk/ukpga/2017/16/contents/enacted

CONTENTS

1.0 POLICY OVERVIEW

1.1 This policy replaces the former Dudley CCG Continuing/Complex Healthcare: Policy and Proforma (2011).

1.2 The purpose of this policy is to ensure that there is a consistent approach to quality, equality and transparency in the assessment and agreement of eligibility for Continuing Care for children and young people registered with a Dudley General Practice (GP).

1.3 This policy must be read in conjunction with the National Framework for Children and Young People's Continuing Care (2016) and other policies mentioned forthwith when assessing the needs of children and young people whose complex needs cannot be met through existing universal or specialist services.

2.0 INTRODUCTION

2.1 This policy describes the way in which 'Dudley Place' (part of the Black Country and West Birmingham Clinical Commissioning Group (BCWBCCG)) assesses and makes provision for the care of children and young people who have been found eligible for NHS Continuing Care as outlined in the National Framework (2016) to ensure that the CCG meets its statutory responsibilities and adheres to good practice guidelines.

2.2 The National Framework for Children and Young People's Continuing Care (2016) sets out principles and processes for its implementation and provides national tools to be used in the assessment. It describes the process for assessing, deciding and agreeing packages of continuing care for children and young people, whose needs cannot be met by universal or specialised services. Continuing care is not available to children or young people whose care needs can be met appropriately through existing universal or specialist health services. In this instance their needs will be addressed using a case management approach from existing service providers.

2.3 When providing support for a child or young person with a SEN/D, Dudley Place (DP) and Dudley Metropolitan Borough Council (DMBC) will work together to assess and coordinate a jointly-agreed package of continuing care and, in doing so, inform the health needs of the child's and young person's Education, Health and Care Plan (EHCP).

2.4 It is essential that all professionals understand how children and young people's continuing care is assessed and that it is commissioned differently to adult's NHS Continuing Healthcare and NHS-funded Nursing Care and the how transitional arrangements from children's to adult's continuing care are addressed.

2.5 This policy describes the processes that will be followed and should be read in conjunction with the following documents:-

- The National Framework for Children and Young People's Continuing Care (2016)
- The Children and Families Act (2014)
- Who Pays? Determining responsibility for NHS payments to providers 2020
- Dudley Adults (18 years +) Continuing Care Policy (2020)

3.0 PURPOSE

3.1 This policy applies to all NHS Continuing Care applications for children aged 0 – 17 (up to the 18th birthday) and are registered with a Dudley GP.

3.2 This policy offers guidance to professionals involved in assessing individuals who may be eligible for continuing care and clarifies the processes for future management of that care, where eligible. It

highlights the responsibilities of DP and DMBC in meeting the continuing care needs of the children and young people.

4.0 POLICY STATEMENT

4.1 BCWBCCG has a legal responsibility for assessing and commissioning, the reasonable healthcare requirements of an individual. This policy describes the process that will be followed so that DP can equitably discharge that responsibility for children and young people with complex needs.

4.2 The CCG is responsible for leading the process of identifying if a child or young person for whom it has a commissioning responsibility under section 3 of the NHS Act 2006, has a continuing care need. However, both BCWBCCG and DMBC have a statutory responsibility to meet the health care, social care and educational needs of children and young people with continuing care needs which may require services commissioned by multiple organisations. It is therefore imperative that DP (BCWBCCG) and DMBC work together to provide a holistic care package adhering to the principle of securing the best outcomes for both the child/young person and their family, however, each organisation remains responsible for its' own statutory duties.

4.3 The Clinical Commissioning Manager for Children, Young People with Complex Needs has overall responsibility for continuing care for children and young people, for overseeing effective liaison with DMBC and other partners, and the management of the process.

4.4 The Continuing Care Nurse Assessor (CCNA) is the single point of contact, with whom professionals can liaise when wishing to discuss a child and young person with possible continuing care needs. The CCNA will coordinate the process ensuring effective management and liaison with local authorities and partners in accordance with the National Framework (2016) and this policy. The CCNA liaises closely with Dudley's Designated Medical Officer (DMO) and Designated Clinical Officer (DCO) for SEND and works closely with professionals in DMBC, to ensure the child or young person has a comprehensive package of care across health, education and social care.

4.5 Continuing care provision is designed to support children and young people with complex needs, to lead an ordinary life where possible, both in the home environment and at school. Health funding to support children and young people in schools, regardless of their eligibility for continuing care support, will be subject to individual consideration and awarded on an individual basis, or as agreed within the child or young person's EHCP.

5.0 SCOPE

5.1 This policy applies to all children and young people from 0-17 years (up to their 18th birthday) with complex health needs that are registered with a Dudley GP and who may have continuing care needs.

5.2 'Continuing care' is a term for a tailor made package of care which is defined in the National Frameworks (2016) 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."

5.3 Some children and young people may have very complex needs. These may be the result of congenital conditions, long-term, life-limiting or life-threatening conditions, disability, or the effects of serious illness or injury. These needs may be so complex, that they cannot be met by services which are routinely available from GP practices, hospitals or in the community, specifically commissioned by the CCG or NHS England. These children or young people may need additional health support. This additional support is known as 'continuing care'.

5.4 Any package of care agreed by DP, or jointly with DMBC, must be sustainable and integrated with other relevant services, such as primary care.

5.5 All health professionals that work directly with children/young people have a duty to ensure that safeguarding and working to promote the welfare of the child or young person forms an integral part of all elements of the care they offer (Working Together to Safeguard Children, 2018).

5.6 All staff working with children and young people will have the necessary training in line with safeguarding policy. Any safeguarding issues are to be reported to the CCG's and DP Designated Senior Nurse for Safeguarding Children and Young People.

6.0 ROLES AND RESPONSIBILITIES

6.1 The National Framework stresses the importance of the child/young person and their family being considered for continuing care, understanding the continuing care process and receiving advice and information in a timely and clear manner.

6.2 Parents and carers, as the experts in their child/young person's care, have the primary responsibility for the care of their child/young person with statutory agencies supporting them to meet the child/young person's identified needs.

6.3 The CCG is responsible for assessing and commissioning continuing care packages to meet the reasonable health care needs of children and young people aged 0-17 years of age who are eligible for continuing care. The needs are identified following a full continuing care assessment using the Decision Support Tool (DST) as stipulated in the National Framework (2016). The CCNA will present the outcome to the Continuing Care Panel for agreement of eligibility and ratification. The panel will consider the evidence and reach a decision as to whether the child or young person has a continuing care need. Following this agreement, the resource allocation tool will be used to assist with assessing the proportion and level of resource required to meet the assessed need. This will be commissioned and the arrangement of provision coordinated through consultation with the child/young person and their family; promoting personalisation.

7.0 EDUCATION, HEALTH AND CARE PLANS

7.1 Children and young people with complex needs may not only need support from health services. They may also have special educational needs. Appropriate care of children or young people with profound multiple disabilities or chronic severe illness involves input from all statutory agencies: Health, Social Care and Education.

7.2 Since September 2014, under section 26 of the Children and Families Act (2014), children and young people (up to 25 years old) with a SEND are entitled to a single plan which consists of a multi-professional assessment to agree an Education, Health and Care Plan (EHCP). The EHCP process has, at its heart, a coordinated assessment of a child or young person's needs, based on multi-professional input and focussed on the outcomes which make the most difference to the child or young person and their family. CCGs and Local authorities must work together to make EHCPs work through joint assessment and arrangement and include an agreement as to how continuing care fits within the EHCP process. The joint assessment will ensure outcomes are established across education, health and social care that the views, interests and aspirations of the child or young person and their family are documented and that collaborative joint working leads to good practice. DMBC remains responsible for conducting an assessment of education, health and social care needs when arranging for specialist educational provision.

7.3 The Code of Practice "Special educational needs and disability code of practice: 0 to 25 years. Statutory guidance for organisations who work with and support children and young people with special educational needs and disabilities" (2014) outlines the statutory guidance for the EHCP process and covers all legal requirements. http://www.gov.uk/government/publications/send-code-of-practice-0-to-25

7.4 Each agency is responsible for their own contributions to the continuing care package or EHCP, in line with their statutory functions. The CCG must work with all agencies to ensure seamless care for a child/young person and their family/carers as far as are practically possible and where appropriate work collaboratively towards a jointly agreed set of outcomes.

8.0 RISK

8.1 DP must endeavour to arrange appropriate tailor-made care packages however, despite best efforts, there may be a delay, where due to lack of resources from providers, for example training.

8.2 As outlined in section 6, parents and carers have the primary responsibility for the care of their child/young person's needs. Therefore, it is important that parents/carers maintain their own competencies to care for their child/young person 24 hours per day. In the event of unforeseen circumstances, when the Continuing Care provider is unable to fulfil a shift, the expectation is that parents/carers have the responsibility to ensure that the needs of their child/young person are met. Should this not be possible, DP will work with DMBC Social Care and other professionals to ensure the child or young person is transferred to a place of safety.

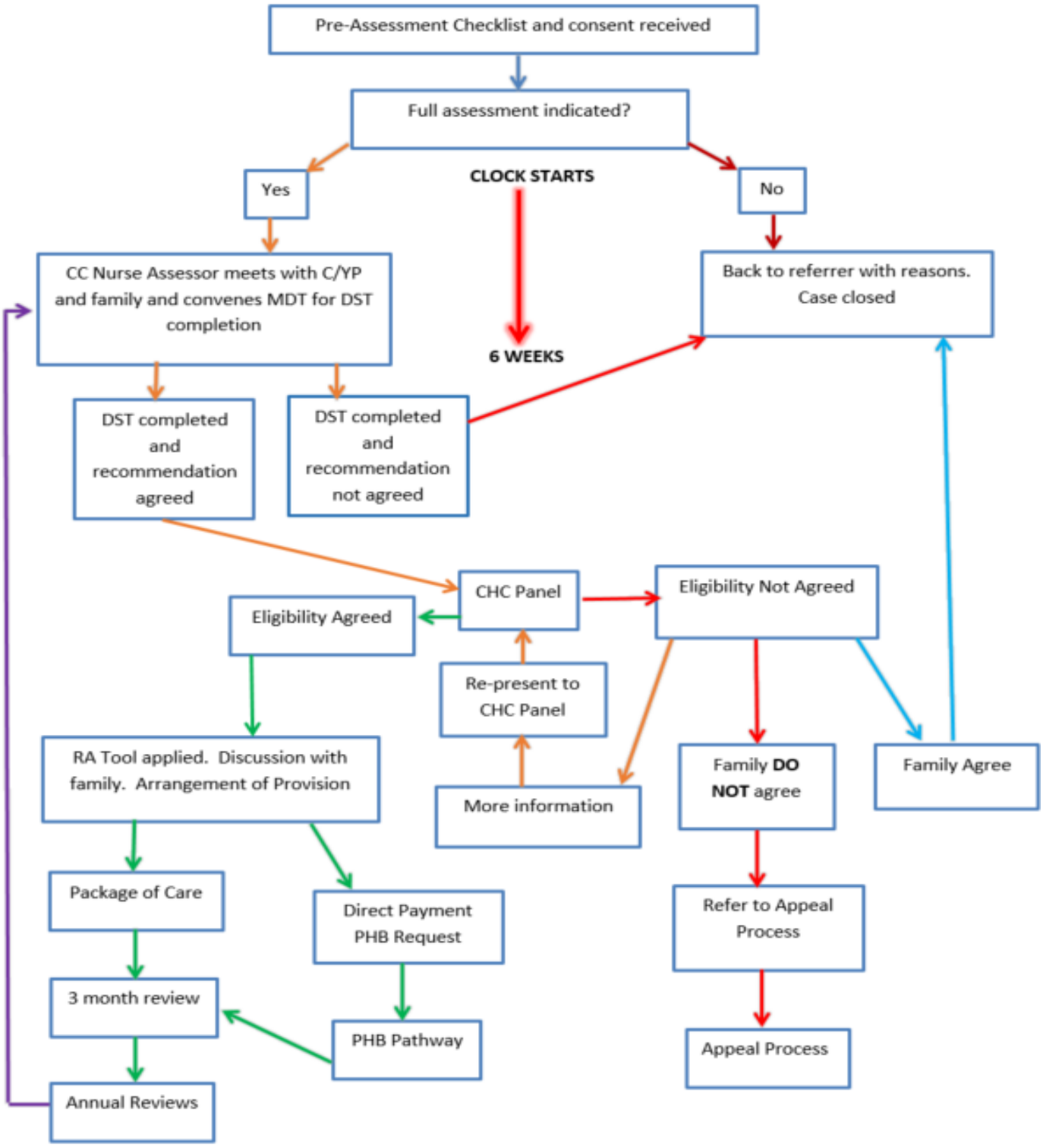
8.3 There may be individual circumstances whereby a child or young person may require support but their health needs may fall outside of the eligibility for continuing care. Under these circumstances it is anticipated that services will be provided under existing contractual arrangements.

8.4 Where a child or young person has a diagnosis specific to the 'Breathing' domain only i.e. Congenital Central Hypoventilation Syndrome (CCHS) or where a 'breathing' need is the only domain to determine eligibility, then the whole Resource Allocation Tool (RAT) will not be utilised and the specific allocation (as detailed within the RAT) will apply. This will be subject to the severity of the diagnosis as classified by a Specialist Consultant.

9.0 CONTINUING CARE PROCESS AND PATHWAY

9.1 The continuing care process determines if a child or young person's needs could be met by universal or specialist services and if not, what additional care is needed. A decision about a child/young person's continuing care need is based on an individual assessment of their health needs. The diagnosis of a particular condition or symptom in itself is not a determinant of a need for continuing care or indicator of the level of need.

Continuing Care Process



Identify

9.2 It is essential that any consideration for Continuing Care is performed via a Multi-Disciplinary Team meeting (MDT) in the first instance. All members of the MDT need to agree to a pre-assessment being carried out.
The checklist requires a minimum of one health professional, parents/carers, social worker and education representative (if applicable).
All enquiries relating to children or young people with possible continuing care needs, or referrals will be sent securely to dihc.cypcontinuingcare@nhs.net using the **Continuing Care Pre-Assessment Checklist'** (appendix 1)

9.3 Parents/Carers will have been given the **Continuing Care Information Leaflet** (appendix 2) and **Appeals Leaflet** (appendix 3) by the referrer, prior to checklist completion.

9.4 Informed consent must be sought prior to completing the pre-assessment checklist. The **'Continuing Care Consent Form'** (appendix 4) must be sent with the completed pre-assessment checklist to the secure email address, dihc.cypcontinuingcare@nhs.net

9.5 The referral should include documentation such as nursing assessments, Health Management Plans, EHCPs, Early Help plans etc. and clearly identify the child or young person's outstanding health needs are not able to be met by universal or specialist services.

9.6 The pre-assessment will indicate whether or not the child or young person should proceed to a full formal assessment.

9.7 If the checklist suggests that the child or young person has needs that can be met by universal or specialist commissioned services, or the checklist has not been completed correctly, correspondence will be sent accordingly to parents/carers and MDT inclusive of rationale, and checklist will be returned to the referrer with details (if required) of appeal process; within 7 working days

9.8 Children or Young People who are entering an End of Life Care phase are not required to undergo pre-assessment and the Fast Track (**Section 12**) pathway should be followed.

Assessment

9.9 Should the pre-assessment checklist indicate that a full assessment (assessment phase) is required, then the CCNA confirm arrangements in writing to the MDT to hold a Continuing Care Assessment (CCA) meeting, with parents/carers and health professionals. The **Children and Young People's Continuing Care Assessment** document (appendix 5) will be used to support the CCA and presented to the Continuing HealthCare Panel (Decision- making phase) for a decision regarding eligibility for continuing care support within 6 weeks from the beginning of the assessment phase.

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

9.11 Any extensions of time required will be discussed with the family and clear explanations given.

9.12 If the child/young person does not have an allocated Social Worker then the CCNA will make a referral to the appropriate authority.

9.13 It is important that the child/young person and/or their family understand that continuing care packages are not indefinite and as the health needs change so may the package of care.

Decision Making

9.14 Following consideration by the Continuing Health Care Panel (CHCP), the decision will be communicated to the family and key professionals verbally and in writing within 5 working days, giving a clear explanation of the rationale for decision.

9.16 The **Resource Allocation Tool (**appendix 6) will be used to establish the amount of health support required based upon the assessed need of the child or young person. Support will be personalised to meet the medical and nursing needs. Continuing Care is a term generally used to describe bespoke care packages in the home. Alternatively, access is available to a Personal Health Budget (**Section 11**) if requested.

9.17 The CCNA and Social Worker will work with the family to arrange appropriate provision and to deliver the package as soon as possible.

9.18 Where appropriate, if an allocated continuing care package exceeds 84 hours per week and the child or young person requires 1:1 care, any hours over the 84 per week must be used to support the child or young person in accessing education. For example, a package of care that is 100 hours per week would have the first 84 hours in the home setting and the remaining 16 hours would provide 1:1 support, ensuring the child or young person can access education safely. If the additional hours are not sufficient for the child or young person to have 1:1 support full-time in education, then the CCG will commission additional school support hours only.

Review

9.18 All packages of care will be subject to review to ensure the developing needs of the child or young person continue to be supported. Reviews are at 3 months following the start of a package and then annually, or in line with transition to appropriate services. They are also responsive to changes in a child or young person's fundamental need. The responsibility to commission care is not indefinite, as needs change eligibility may change as well, resulting in a change to the nature of the care required. This will be made clear to the child or young person and their family. In instances where transition back to universal or specialist health services is appropriate, the child or young person and their family will be supported throughout by their existing care team.

9.19 The child or young person and/or their family/carer reserve the right to have the needs assessed earlier should it be felt the health needs have changed prior to review.

9.20 Should a child/young person be admitted to an acute hospital, the package of care can continue within the hospital setting for a 2 week period, providing both the Clinical Commissioning Manager for Children and Young People with Complex Needs and the Acute Hospital are in agreement. If the child or young person is not likely to return home within the 2 week period, then further negotiation with the Clinical Commissioning Manager for Children and Young People with Complex Needs is required.

10.0 TRANSITION

10.1 Once a young person reaches the age of 18 years, they are no longer eligible for Continuing Care for children and young people but may be eligible for Adult NHS Continuing Healthcare, which is subject to its own legislation and specific guidance.

10.2 It is important that young people and their families are helped to understand that eligibility to Children's Continuing Care does not automatically imply eligibility to Adult NHS Continuing Health Care and the implications of this will be made clear right from the start of transition planning.

- At 14 years of age, the young person will be brought to the attention of the CCG's Adult NHS Continuing Healthcare Team using the **Continuing Care Transition Notification Form** (appendix 7).

- At 16 years of age, screening for Adult 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 will have been made.
- At 18 years of age, full transition to Adult NHS Continuing Healthcare or to universal and specialist services will have been made, except in instances where this is not appropriate.

10.3 Where the young person has an allocated Children's Disability Team Social Worker, they will lead the transition process, working alongside the identified Transition Team Social Worker.

11.0 PERSONAL HEALTH BUDGETS

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

11.2 Where a child or young person is found eligible for continuing care and requests a personal health budget, this must be requested via the **'Children and Young People's Continuing Care Personal Health Budget: Expression of Interest Form'** (appendix 8).

11.3 Interim support will be offered while a personalised package through PHB is set up.

11.4 The family have the right to request a PHB at any time during the time their child or young person has a package of care and will be discussed at reviews.

11.5 Once the PHB Expression of Interest Form has been submitted, the CCNA will then arrange to discuss the indicative budget and support plan, and agree outcomes developed with the child/young person and/or their family. The meeting will also discuss which type of PHB the family are interested in. A PHB can be made available in a number of ways.

- A **direct payment** made to the young person or their family;
- The agreement of a **notional budget** to be spent by the CCG following discussions with the child or young person, and their family (or other representative) as to how best to secure the provision needed;
- The transfer of a **real budget** agreed as above, to the person or organisation which applies the money in a way agreed between the CCG and the child or young person, and their family (or other representative).

11.6 The completed support plan will then be submitted to DCCG PHB Panel for decision. Once the support plan is agreed at PHB Panel then the final budget will be confirmed and finance informed. Direct payment agreements must be signed off (direct payment or real budget) by the Chief Finance and Operating Officer, or his representative, before the budget can start. A PHB is subject to the same review process as continuing care packages of care and therefore if a child/young person is no longer eligible for continuing care, the PHB will cease and a transition plan for support from existing universal or specialist services will be implemented.

11.7 The CCG is only obliged to provide services that meet the assessed needs. A parent/carer has the right to decline NHS funded services and make their own private arrangements.

11.8 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

12.0 FAST TRACK

12.1 End of Life care refers to a rapidly deteriorating condition characterised by an increasing level of dependency, whereby the lifespan is thought to be days or weeks rather than months or years.

12.2 Any child or young person deemed to be requiring End of Life Care will require a Fast Track assessment for immediate provision of continuing care. In these cases the **'Children and Young People's Continuing Care Fast Track'** documentation (appendix 9) will be completed by the appropriate professional and sent to;-
dihc.cypcontinuingcare@nhs.net.

12.3 The CCNA will discuss the case immediately with the Clinical Commissioning Manager- Children and Young People with Complex Needs and determine appropriate provision. In emergency cases, the CCNA or any other person acting with the authority of Dudley CCG Managing Director, or any other executive director, can agree continuing care provision outside of the usual process with notification and discussion afterwards.

13.0 DISPUTES, APPEALS AND COMPLAINTS PROCESS

13.1 In the event of a decision which did not meet their preferences and/or expectations, the child/young person and their family will have been informed of their rights and of the complaints procedure.

Complaints

13.2 Should a child/young person and/or their family wish to complain about a package of care or a service already being provided or commissioned, they should make this known to the CCNA. The CCNA will work with the family to resolve the complaint.

Appeals

13.3 The decision from the Continuing Health Care Panel, will be communicated in writing within 5 working days stating whether or not the child/young person has met continuing care eligibility or not.

13.4 Where an application has been found ineligible, individual patients, or their representative can appeal in writing within 6 months of the notification of the decision.

13.5 Appeals should be sent to:

Clinical Commissioning Manager: Children and Young People with Complex Needs
Dudley Integrated Health and Care NHS Trust, 2nd Floor
Brierley Hill Health and Social Care Centre
Venture Way,
Brierley Hill
DY5 1RU.

Email: dihc.cypcontinuingcare@nhs.net

Stage 1: First Line Appeal

13.6 When an appeal is received this is acknowledged and a meeting is arranged with the CCNA to discuss the areas of contention.

Stage 2: Informal Resolution Meeting

13.7 If the appeal is not resolved at this stage, an offer of an informal resolution meeting is made with the individual patient or their representative, the CCNA and the Clinical Commissioning Manager for Children and Young People with Complex Needs to go through the decision-support tool (and resource allocation tool, where appropriate) and rationale for the decision.

13.8 If the family wish for additional information to be considered then the CCNA will update the assessment (where appropriate) and re-present this to the next Continuing Healthcare Panel for a review of the decision.

Stage 3: Local Review Panel

13.9 If the parent/carer remains dissatisfied following the Informal Resolution Meeting, A hearing will be arranged with DP (BCWBCCG) Independent Review Panel (IRP). The members of the review panel will be independent of the initial decision makers that reviewed the eligibility application.

13.10 The patient or their representative will be asked to submit evidence on why they disagree with the decision and to specify those areas of disagreement.

13.11 The CCG and the child/young person and/or their family/carer will be asked to present their respective cases to the IRP. Families are encouraged to attend the IRP meetings to present their case and participate in the discussions.

13.12 The IRP tasks are, at the request of the CCG Board, to conduct a review of the following:-

a) The procedure followed by BCWBCCG in reaching a decision as to that persons eligibility for continuing care; and/or

b) The primary health need decision by BCWBCCG

13.13 The IRP will make a recommendation to the Board in the light of its findings on the above matter.

13.14 The terms of reference for the panel are as follows:-

"To consider and determine any appeal against a decision regarding the package of care awarded for Children and Young People's Continuing Care."

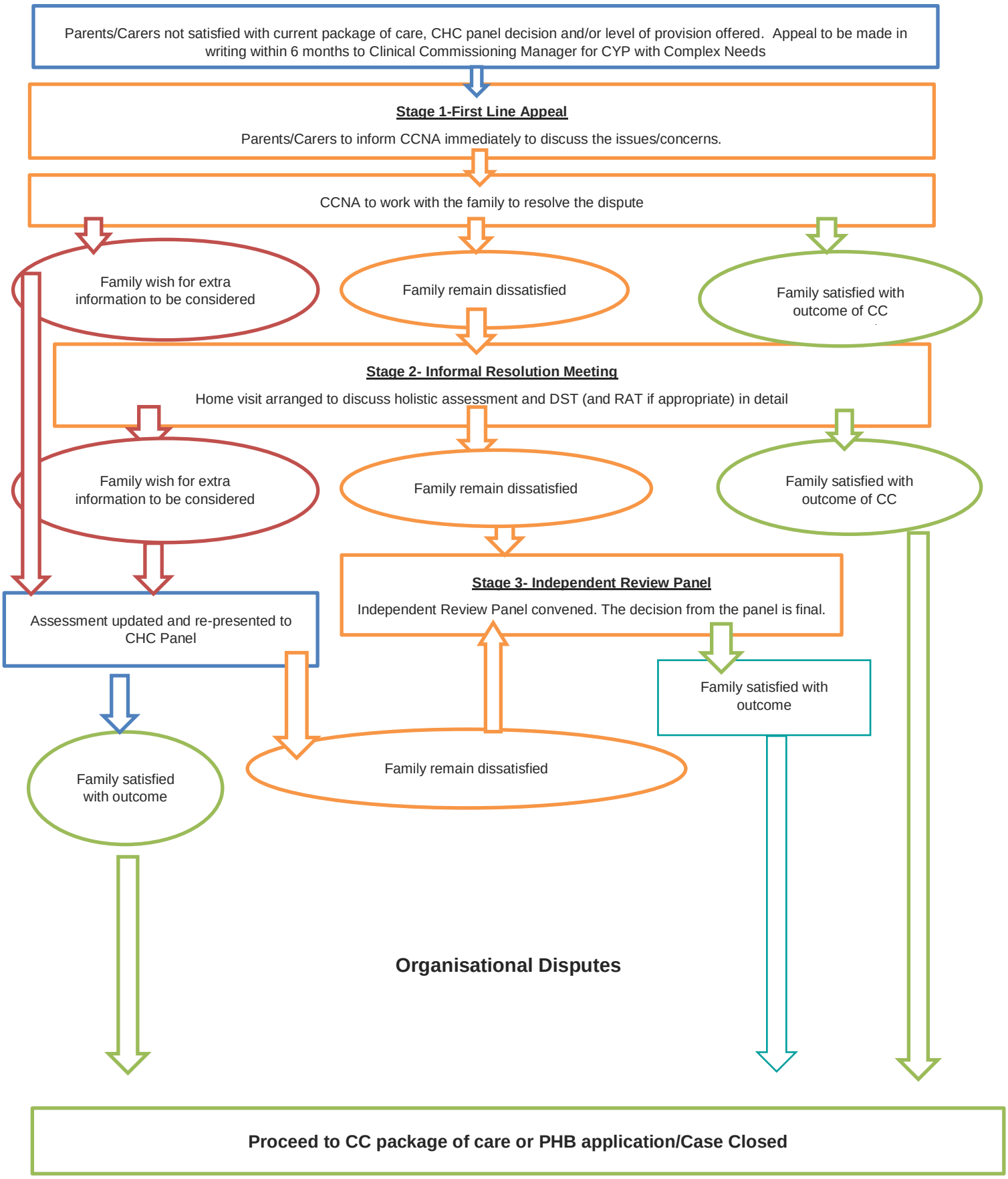
13.15 Before an IRP can be convened, all appropriate steps must have been taken by DP (on behalf of BCWBCCG) to resolve the case at local level.

13.16 The existing package of care will remain unchanged until the appeal process is concluded.

13.17 The Local Authority and their employees are not able to appeal against the decisions made by DP (BCWBCCG) on behalf of a child, young person or their representative. Appeals may only be made by the individual applicant themselves or their representative. There is a separate dispute resolution process for the Local Authority – details of which are outlined in the next section.

13.18 The decision from the Local Review Panel is final.

NHS Dudley CCG Appeals Process



Organisational Disputes

13.19 Continuing care arrangements have the potential to generate disputes regarding responsibilities for health, social care and education funding.

13.20 The National Framework for Children and Young People's Continuing Care (2016) states that disputes about who should have commissioning responsibility should be resolved through escalation to relevant executives, or through the involvement of impartial peers.

13.21 In line with the Haringey judgement, there are clear limits to what care should be funded by the local authority, which should not be a substitute for additional NHS care for children.

13.22 A separate procedure is in place to resolve appeals from individuals or their authorised representatives as set out above. The procedure described below cannot be used to make an appeal on the individual's behalf.

13.23 If the individual (their representative or an independent advocate) makes a formal appeal at the same time or subsequent to a dispute registered by the Local Authority, the appeal by the individual, their representatives or independent advocate will take precedence and will follow the appropriate Appeals Procedure.

13.24 The key objective of the CCG and the LA is to ensure that an individual's eligibility for NHS Continuing Care is correctly determined based on the assessment of their care needs and that the assessment of these needs has followed due process, as outlined in the NHS National Framework.

13.25 The following key principles apply:-

- to encourage a culture of problem solving, collaboration and close partnership working that demonstrates openness, consistency and transparency throughout the CHC process.

- formal disputes should be the last resort and should seldom be necessary if the NHS National CHC Framework is adhered to;

- The Multi-Disciplinary Team members involved with each patient should endeavour to work together to undertake the CHC Assessment and consider the evidence to support decision making. The outcome of the CHC assessment should be agreed by the professionals and other people involved with the individual who have the best knowledge and understanding about the individual's care needs;

- If the MDT is unable to reach a decision on the outcome of the CHC Assessment then this will be recorded on the DST (Decision Support Tool) with the views of the MDT members, including noted disagreements.

- The individual should not be involved in the dispute in any way. In such cases they should be informed of the DCCG's decision on eligibility in the normal way, giving them the opportunity to formally appeal if they wish to in their own right;

- Individuals should always be cared for in an appropriate environment throughout the process and any dispute in relation to funding should not interfere with the support provided to them.

The Disputes Process

13.26 The process of considering and deciding eligibility for NHS Continuing Care must not delay treatment or appropriate care being put in place. The agreed arrangements therefore are based on the following principles:-

- neither the CCG nor the LA will unilaterally withdraw from funding an existing package until the dispute is resolved;

- the individual will be discharged from hospital as soon as they are ready to go to their home, residential care etc. The dispute process must not delay discharge of a patient if support can be arranged prior to the dispute being resolved;

- the LA and CCG will work together to agree case management arrangements to ensure the individual continues to receive the best and most appropriate support to meet their needs at all times;

- in the event of a dispute between the CCG and the LA, the placement will be funded without prejudice pending a final decision. Reimbursement will be made as required from the date that the dispute was registered.

13.27 For disputed cases the placement / care package will be funded for the duration of the dispute by:-

- The current funding body (e.g. if individual was funded by the CCG as NHS Continuing Care before admission, CCG would fund on discharge. Likewise for the LA if a comparable package of care was funded by the LA);

- If there was no funding responsibility before admission or no comparable care package CCG will fund on discharge for patients who require nursing care and the LA will fund care at home, in residential care or supported living without prejudice;

- The LA will undertake a full Community Care Assessment for disputed cases and provide a copy of the assessment to the CCG, without delay;

- The LA must send a formal notice of dispute to the Clinical Commissioning Manager, setting out the reasons why it is considered that the CC assessment is incorrect or has not followed due process in line with the NHS National CC Framework (2016).

Dispute Panel Arrangements

13.28 The arrangements for resolving disputes via a dispute panel should be on an exceptional basis. Every effort should be made for the dispute to be resolved by discussion between CCG CCNA, Social Worker and other members of the MDT who have direct knowledge of the individual and are conversant with his / her health care and support needs.

13.29 The dispute process must not delay discharge of a patient if a care package is ready prior to the dispute being resolved.

Dispute Stage	Process	Timescale
Stage 1	The Clinical Commissioning Manager CYP Complex Needs and the Children's Social Care Service Manager meet with the CCNA and Social Worker to discuss the assessment, process followed and evidence to support the completion of the DST (Decision Support Tool). Progress to Stage 2 if not resolved.	Within 5 working days
Stage 2	The Commissioning Manager: Children Young People and Families and Social Care Leads for Continuing Care to meet with Clinical Commissioning Manager CYP Complex Needs and the Children's Social Care Service Manager to try to agree a resolution. Progress to Stage 3 if not resolved.	Within 10 working days

At Stage 2, the respective CC Leads can elect to resolve the matter by arbitration, mediation or independent review if considered appropriate.		
Stage 3	Independent Review Panel to be convened consisting of: • Managing Director Dudley Place BCWBCCG • Assistant Director, or Head of Service-Children's Social Care • A Consultant in Public Health Medicine (Independent Person) • A Senior Manager from Children's Social Care (CDT Manager) • Commissioning Manager: Children Young People and Families Progress to Level 4 if not resolved.	Within 28 working days
At Stage 3, the respective Directors/Chief Officers can elect to resolve the matter by arbitration, mediation or independent review if considered appropriate.		
Stage 4	Discussion between Chief executive of the CCG and the Director of DACHS	Within working 10 days
At Stage 4, the Chief Executive and the Director of Social Care can elect to resolve the matter by arbitration, mediation or independent review if considered appropriate. This can include a "Peer Review" of the process, evidence and decision making process from another CCG.		

13.30 The dispute process does not affect the legal rights of either party to take further action or to pursue the concerns via a formal complaint to NHS England.

13.31 There will be agreement that any learning from IRP and the Dispute Process will be taken positively to inform future and best practices for the benefits of individuals and support cohesive working relationships across DMBC and CCG.

13.32 If at the end of the dispute process NHS Continuing Care funding is agreed it will be payable from the date that the assessment was undertaken and not from the date of the conclusion of the dispute process.

13.33 It is the responsibility of DMBC and CCG to provide updated full information at each stage of the dispute process so that decision making is not delayed by absence of information or evidence.

Appendices

APPENDIX	TITLE
1	National Frameworks (2016) Children and Young People's Continuing Care Pre-Assessment Checklist
2	Children and Young People's Continuing Care Information Leaflet
3	Children and Young People's Appeals Process leaflet
4	Children and Young People's Continuing Care Consent Form
5	National Frameworks (2016) Decision Support Tool
6	Dudley CCG's Resource Allocation Tool
7	Continuing Care Transition Notification Form
8	Children and Young People's Continuing Care Personal Health Budget: Expression of Interest Form
9	Children and Young People's Continuing Care Fast Track

Children and Young People's

Continuing Care

Pre-assessment Checklist

Pathway for Children and Young People's Continuing Care

It is essential that any consideration for Continuing Care is performed via a Multi-Disciplinary Team meeting in the first instance

Multi-Disciplinary Team (MDT) complete pre-assessment checklist.
All members need to agree to a pre-assessment being carried out, this should only take a day or two.

The completed checklist should be sent to:
Commissioning Support Manager for Children & Young Persons Continuing Care who will review and determine if the checklist indicates progression to full Continuing Care Assessment (CCA)

***Guidance* to indicate full CCA/DST completion (3 highs, 1 severe or 1 priority**), *alongside information regarding unmet health* need

Yes

CYPCC to confirm arrangements by letter to MDT to hold a CCA meeting, inclusive of parent(s)/carer(s)

Continuing Care Assessment (CCA) completion.
CCA should demonstrate current needs, and ideally should not surpass needs identified within a 28 days timespan from date of completion; *providing a current*

No

If the checklist suggests that the child or young person has needs that can be met by universal or specialist commissioned services, or the checklist has not been completed correctly correspondence will be sent accordingly to parents/carers and MDT inclusive of rationale, and checklist will be returned to the referrer with details (if required) of appeal process; within 7 working days

Abbreviations

CCA	Continuing Care Assessment (assessment carried out to establish what needs a child or young person has; at that moment in time.
CAMHS	Child and Adolescent Mental Health Service
CCG	Clinical Commissioning Group (*clinically*-led statutory NHS bodies responsible for the planning and *commissioning* of health *care* services in their local area)
CYPCC	Children and Young Person's Continuing Care
DIHC	Dudley Integrated Health and Care NHS Trust
DST	Decision Support Tool (the tool that is used within the process to assess needs)
EHCP	Education Health Care Plan (the plan for children and young people aged up to 25 who need more support than is available through special educational needs support. This plan identifies the educational, health and social needs that are required and sets out the additional support to meet those needs)
LAC	Looked After Child
MDT	Multi-Disciplinary Team (group of professionals who provide support to child/young person and to parents)
OT	Occupational Therapist
SEND	Special Educational Needs and Disabilities

Children and Young People's Continuing Care

Checklist Documentation and Information

You are reading this document because as a Multi-Disciplinary Team you have identified that a child or young person has a health need **that cannot be met by universal/specialist services**, this is **the first stage** of the Continuing Care Process. The checklist documentation contains information, which will capture the individual needs of the child or young person.

Checklist completion requires **a minimum of one** health professional, parents/carers, social worker and education representative (if applicable). **The checklist should never be completed by an individual professional alone** to ensure universal and commissioned services have been pursued, and parents and MDT collectively agree to checklist completion, based upon a fully informed discussion with all relevant persons present.

Important information regarding process

After completion of the pre-assessment checklist the Children and Young People's Continuing Care (CYPCC) team will contact the Parents/Carers (or who has parental responsibility) by letter (members of the MDT will be copied into the letter). A meeting will be arranged (if there is an indication to proceed to a full Continuing Care Assessment - CCA). **Please note that indication to proceed to a CCA does not mean that the CYP will be eligible for Continuing Care.**

The CCA is the formal application which, once completed, will be further quality assured by the Continuing Care nurse, and thereafter forwarded to the next CYPCC Panel.

CYPCC will need a health professional to remain involved whilst the child or young person is on the Continuing Care caseload.

All enquiries and completed forms to be returned electronically to:

Email: dihc.cypcontinuingcare@nhs.net

Contact Number: 01384 322606

Children and Young People's Continuing Care Pre-Assessment Checklist

PERSONAL DETAILS				
Family Name:		Given Name(s):		
DOB		Gender	Female	Male
Ethnicity		Language		
Advocacy required?	Yes / No	Is an interpreter needed?	Yes / No If Yes, what language?	
NHS Number		Social Worker		
		Social Care Number		
Family Address (including e-mail)		Current Address (if different)		
Post Code		Post Code		

Family Members/Significant Others/Contacts		
Name	Relationship	Contact Details
Supportive Extended Family		
Emergency Contact Name		Telephone

GP DETAILS	
Name of GP *(if child or young person has a named doctor)*	
Address of GP practice	

Clinical Commissioning Group	
Local Authority	
Education	

MEDICAL HISTORY
Provide a brief summary below of the child or young person's primary health needs, with details of any diagnoses and provision.

SOCIAL CARE
Provide a brief summary below of the child or young person's social care needs with details of any arrangements in place. Include any **safeguarding concerns or risks** related to homecare provision.

EDUCATION	
Name of nursery, school or college attending	
Year group	
Contact details (where known)	
What additional support or reasonable adjustments are required in that setting? *Please indicate if the level of healthcare provision exceeds what the school can provide for (but not linked with funding/capacity) i.e. if a child is ventilated throughout the day.*	
Does the child or young person have special educational needs? Yes /No	
Is there an Education Healthcare Plan (EHCP) in place? Yes /No	
If there is what is the date of the last review:	

CONSENT

Please obtain verbal and signed consent *(This referral cannot be accepted without consent)*	**Child / Young Person**		**Parent / Carer**	
Are they aware that a referral has been made and consented to the sharing and obtaining of information to support this application? *(delete as appropriate)*	Yes	No	Yes	No
Have parents/carers been involved/contributed to the completion of this checklist? *(delete as appropriate)*	Yes	No	Yes	No
Has the signed consent form been attached to the application – please highlight the answer if the form has been typed? *(this will be required to proceed)*	Yes	No	Yes	No

Are there any agencies that parents do not want to be referred to within this pre-assessment?	

Parent/Carer signature/s (or those with parenting responsibility) and names printed in full

	Signature	Print name	Date
1.			
2.			
3.			

Child/Young Person's signature and name printed in full (if applicable)

Signature	Print name	Date

DETAILS OF CHECKLIST	
Date of checklist *(completion)*	

Name of Lead Professional completing documentation *(Use the box below for details of other contributors.)*		**Profession**		
Address				
Employer				
Contact number				
E-mail address *(secure, if possible)*				
Signature				
Health professional involved if not Lead Professional	**Name**		**Role**	
	Email			
	Contact number			

DETAILS OF PRE-ASSESSMENT	
Date of pre-assessment (completion)	

Name of assessor (use the boxes below for details of other contributors)	
Contact no.	
E-mail	
How was the referral for continuing care made?	

EXISTING ASSESSMENTS
Provide details below of any relevant assessments made in the last 2 years (e.g. CAF, Education, Health and Care plan or Statement of SEND, CAMHS assessments). Summary plans or other evidence can be attached.

Health		Education		Social Care	
	CAMHS assessment		EHC Plan		Child in Need
	OT assessment		Educational Psychology		Child in Care

	Physio assessment		School targets		Child Protection
	SALT assessment		School report		Early Help

Looked After Child (documents for review purposes in reference to children/young people who are placed by Local Authority and in receipt of Continuing Care support).

	Compliance review
	Independent Review (by Independent reviewing Officer)
	Annual health review (Looked After Children's Nurse)
	EHCP annual review

OTHER:

BREATHING	
Description	**Level of need** (please highlight)
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;	Severe

or 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.	
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.	Priority
Please provide a brief rationale for the level of need:	Level:

EATING AND DRINKING	
Description	**Level of need** (please highlight)
Able to take adequate food and drink by mouth, to meet all nutritional requirements, typical of age.	No additional needs
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;	Low

or needs feeding when this is not typical for age, but is not time consuming or not unsafe if general guidance is adhered to.	
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.	Moderate
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.	High
The majority of fluids and nutritional requirements are routinely taken by intravenous means.	Severe
Please provide a brief rationale for the level of need:	Level:

MOBILITY	
Description	**Level of need** (please highlight)

Mobility typical for age and development.	No additional needs
Able to stand, bear their weight and move with some assistance, and mobility aids. **or** moves with difficulty (e.g. unsteady, ataxic); irregular gait.	Low
Difficulties in standing or moving even with aids, although some mobility with assistance. **or** 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; **or** 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.	Moderate
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; **or** at a high risk of fracture due to poor bone density, requiring a structured management plan to minimise risk, appropriate to stage of development; **or** involuntary spasms placing themselves and carers at risk; **or** extensive sleep deprivation due to underlying medical/mobility related needs, occurring every one to two hours (and at least four nights a week).	High
Completely immobile and with an unstable clinical condition such that on movement or transfer there is a high risk of serious physical harm; **or** positioning is critical to physiological functioning or life.	Severe

Please provide a brief rationale for the level of need:	Level:

CONTINENCE OR ELIMINATION	
Description	**Level of need** (please highlight)
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
Please provide a brief rationale for the level of need:	Level:

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; use of the stoma should be considered under the domain **Continence or elimination**. In the same way, 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 (e.g. use of suction), should be considered under **Breathing.**	
Description	**Level of need** (please highlight)
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

Please provide a brief rationale for the level of need:	Level:

COMMUNICATION	
Description	**Level of need** (please highlight)
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.	No additional needs
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. Family/carers may be able to anticipate needs through non-verbal signs due to familiarity with the individual.	Low

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. **or** support is **always** required to facilitate communication, for example, the use of choice boards, signing and communication aids. **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.	Moderate
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.	High
Please provide a brief rationale for the level of need:	Level:

DRUG THERAPIES AND MEDICATION	
Description	**Level of need** (please highlight)
Medicine administered by parent, carer, or self, as appropriate for age.	No additional needs
Requires a suitably trained family member, formal carer, teaching assistant, nurse or appropriately trained other to administer medicine due to • age • non-compliance • type of medicine; • route of medicine; and/or • site of medication administration	Low
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; **or** monitoring because of potential fluctuation of the medical condition that can be non-problematic to manage; **or** sleep deprivation due to essential medication management – occurring more than once a night (and at least twice a week).	Moderate
Drug regime requires management by a registered nurse at least weekly, due to a fluctuating and/or unstable condition; **or** sleep deprivation caused by severe distress due to pain requiring medication management – occurring four times a night (and four times a week). **or** requires monitoring and intervention for autonomic storming episodes.	High
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; **or** extensive sleep deprivation caused by severe intractable pain requiring essential pain medication management – occurring every one to two hours **or** requires continuous intravenous medication, which if stopped would be life threatening (e.g. epoprostenol infusion).	Severe

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.	Priority
Please provide a brief rationale for the level of need:	Level:

PSYCHOLOGICAL AND EMOTIONAL NEEDS Interpretation point: a separate domain considers Challenging Behaviour, and assessors should avoid double counting the same need.	
Description	**Level of need** (please highlight)
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; **or** 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).	Moderate
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; **or** 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.	High
Please provide a brief rationale for the level of need:	Level:

SEIZURES	
Description	**Level of need** (please highlight)
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

Please provide a brief rationale for the level of need:	Level:

CHALLENGING BEHAVIOUR	
Description	**Level of need** (please highlight)
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 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
Please provide a brief rationale for the level of need:	Level:

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

Care Domain	N	L	M	H	S	P
Breathing						
Eating and drinking						
Mobility						
Continence or Elimination						
Skin and Tissue Viability						
Communication						
Drug Therapies and Medicines						
Psychological and Emotional Needs						
Seizures						
Challenging Behaviour						
Totals						

Care Category please circle

PD Physical disability	LD Learning disability	MH Mental health	Palliative/EOL End of life care

Following the MDT what are the identified unmet health needs?

IMPORTANT INFORMATION TO NOTE RE: CCA MEETING

Please provide a list of attendees required at the MDT:

If on reviewing the completed Checklist or at the CCA meeting it becomes evident that all universal and specialist services have **NOT** been explored the process would stop at this point and therefore the application would stop. Once universal and specialist services have been explored and there is evidence of an unmet health need, a new application may be submitted to the Continuing Care team.

The Continuing Care nurse will need all persons from the MDT to fully participate thereafter in the CCA completion in order to collate the relevant information and to sign the completed document. If this is not possible, the meeting may have to be reconvened and restarted at a later date. Please note that this may hold up the process of the CCA being heard at the next panel. **A health representative is required to be present throughout the meeting to agree the level of health needs across all domains.**

If other individuals / organisations support the child or young person, and have contributed to the pre-assessment, please give details below. Please highlight any person who will be forwarding a report in readiness for the DST completion.

Please ask attendees at checklist completion to complete the following along with their signature

1.	**Name:**
	Address:
	Organisation:
	Role in relation to the child or young person:
	Nature of contribution *(e.g. report, advice, multi-professional team meeting etc.)*
	Contact No:
	E-mail address:
	Signature:

2.	**Name:**
	Address:
	Organisation:
	Role in relation to the child or young person:

	Nature of contribution *(e.g. report, advice, multi-professional team meeting etc.)*
	Contact No:
	E-mail address:
	Signature:

3.	**Name:**
	Address:
	Organisation:
	Role in relation to the child or young person:
	Nature of contribution *(e.g. report, advice, multi-professional team meeting etc.)*
	Contact No:
	E-mail address:
	Signature:

4.	**Name:**
	Address:
	Organisation:
	Role in relation to the child or young person:
	Nature of contribution *(e.g. report, advice, multi-professional team meeting etc.)*
	Contact No:
	E-mail address:
	Signature:

5.	**Name:**
	Address:
	Organisation:
	Role in relation to the child or young person:
	Nature of contribution *(e.g. report, advice, multi-professional team meeting etc.)*
	Contact No:
	E-mail address:
	Signature:

6.	**Name:**
	Address:
	Organisation:
	Role in relation to the child or young person:
	Nature of contribution *(e.g. report, advice, multi-professional team meeting etc.)*
	Contact No:
	E-mail address:
	Signature:

7.	**Name:**
	Address:
	Organisation:
	Role in relation to the child or young person:
	Nature of contribution *(e.g. report, advice, multi-professional team meeting etc.)*

	Contact No:
	E-mail address:
	Signature:

8.	**Name:**
	Address:
	Organisation:
	Role in relation to the child or young person:
	Nature of contribution *(e.g. report, advice, multi-professional team meeting etc.)*
	Contact No:
	E-mail address:
	Signature:

To be completed by Continuing Care Nurse Assessor

Accepted for progression to DST **Yes/No**

Rationale

OR

Further Information Required

Completed By

Date

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.

If you wish to discuss any aspect of continuing care please contact:

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 2016

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 that the care available, or whether or not they have a particular condition.

NHS
Dudley
Clinical Commissioning Group

Children and Young People's Continuing Care

Complaints/Appeals Process

Parents/carers, children and young people will be involved, where possible, within the Continuing Care assessment and decision-making process. Sometimes decisions are not as expected. You should follow the advice below should you wish to make a complaint or appeal a decision.

Complaints

Should you have a complaint or dispute about a package of care or service already being provided, please make contact with the Continuing Care Nurse Assessor for discussion on 07554 773945.

Appeals

Should you wish to appeal a decision following the Continuing Healthcare Panel, you should follow the below process, clearly stating the reason for the appeal.

Appeals should be made in writing, within 6 months of the notification of the decision to:

Clinical Commissioning Manager for Children and Young People with Complex Needs

Dudley Integrated Health and Care NHS Trust, 2nd Floor

Brierley Hill Health and Social Care Centre

Venture Way,

Brierley Hill

DY5 1RU.

Or via Email to: **dihc.cypcontinuingcare@nhs.net**

Stage 1: First Line Appeal

A meeting will be arranged with the Continuing Care Nurse Assessor to discuss the areas of contention.

Stage 2: Informal Resolution Meeting

If the appeal is not resolved in Stage 1 then an informal resolution meeting will be arranged with the Continuing Care Nurse Assessor and the Clinical Commissioning Manager for Children and Young People with Complex Needs, and the assessment and decision-support tool will be discussed in detail and where possible seek agreement. If you wish for additional information to be considered then the Continuing Care Nurse Assessor will update the assessment (where appropriate) and re-present this to the next Continuing Healthcare Panel for review of the decision.

Stage 3: Local Review Panel

If you remain dissatisfied or there is no agreement a hearing will be arranged at the Independent Review Panel by Dudley CCG. Each party will present their cases. The decision from the Independent Review Panel is final.

Children and Young People's Continuing Care

Consent Form

Guidance for Completion

- **Consent must be obtained prior to the completion of the pre-assessment checklist and if required, a full Continuing Care Assessment. A referral cannot be considered without consent.**
- **This consent, if given, will be used to request information from a variety of sources including GP, Hospital Doctors, Social Care, Allied Health Professionals etc. should full assessment be indicated via email, telephone or post.**
- **All information is confidential and shared only as part of the eligibility process, decision making and for purposes of procuring care and treatment and payment processing.**

- I/we have read the Children and Young People's Continuing Care Information Leaflet

- I/we give consent for information to be obtained from and/or shared with all relevant health professionals/agencies with regard to an application for continuing care funding. I/we understand that professionals will endeavour to send information confidentially but I/we am/are aware that, at times, personal details may need to be sent via unsecure email addresses from one professional to another. (i.e. Education to NHS) and that shared information will be stored electronically.

- I/we consent to the relevant professionals being contacted and information being shared for the purpose of the continuing care assessment, decision-making and (where applicable) the arrangement of provision process.

- I/we have read and understood the Children and Young People's Continuing Care Appeal Process leaflet and understand my/our responsibility should I/we disagree with any decision made.

- I/we understand that consent can be withdrawn at any time but reserve the right to request an assessment in the future. I/we understand that eligibility for NHS Continuing Care cannot be determined until assessment is completed and agreed and that any assessment cannot be back dated.

- I/we agree that a referral to Social Care can be made should it be necessary for a joint assessment in view of securing appropriate support for my/our child/young person.

About the Child/Young Person			
FULL NAME:			
ADDRESS (inc. Postcode):			
NHS NUMBER:		DATE OF BIRTH:	
REGISTERED GP PRACTICE:			
Has the child/young person consented to information sharing of their personal confidential data?	YES		
	NO		

If this form has not been signed by the above person, please give the following information about the person completing and signing the form on their behalf.

I/we confirm that I/we have parental responsibility/authorised capacity	
CHILD/MOTHER/FATHER/GUARDIAN (delete if not applicable) OTHER-Please state:	
Mr/Mrs/Miss/Ms	Persons Name:
Address (if different from above):	Contact Telephone No:

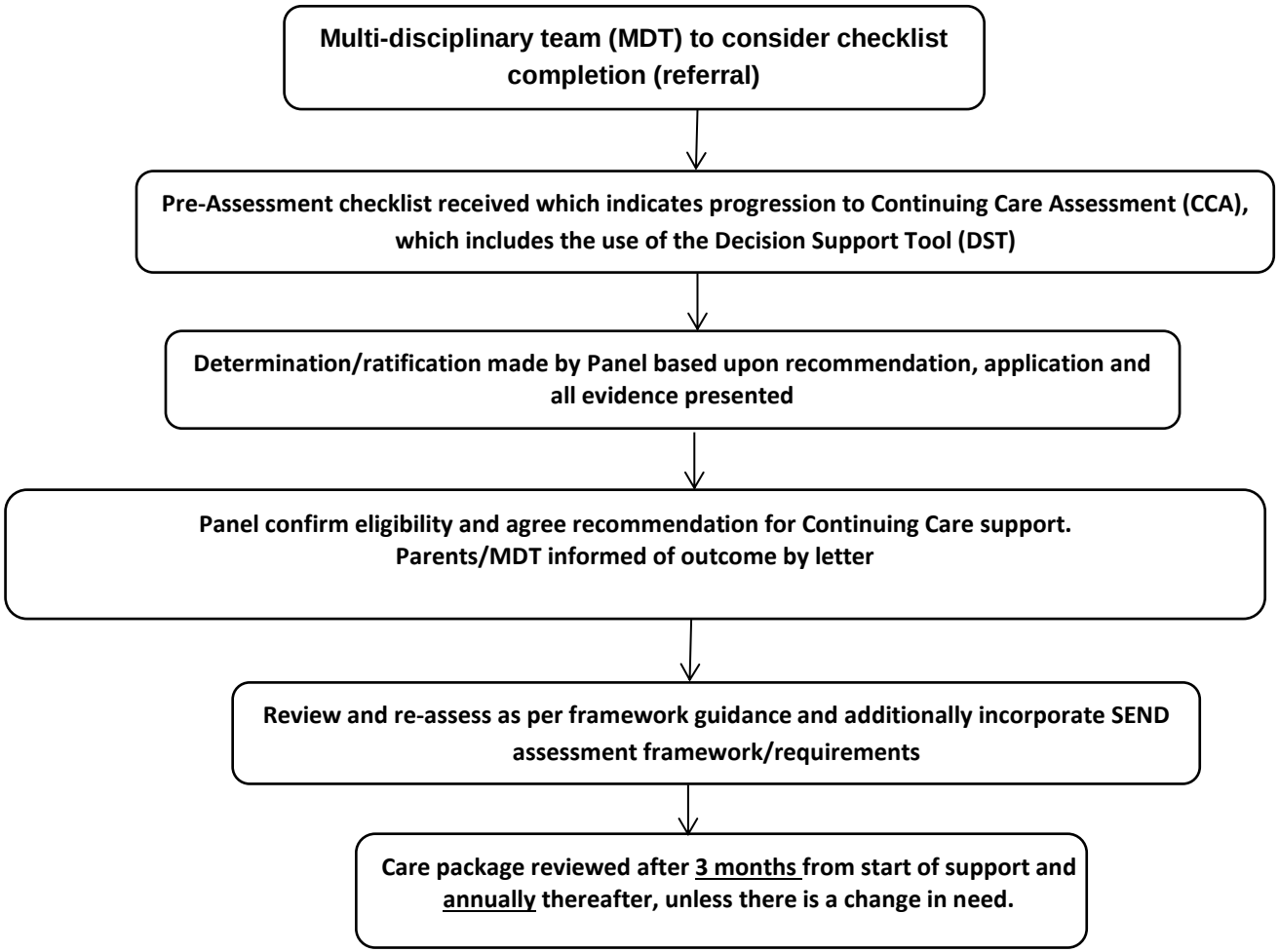
Accept Assessment- Please read and sign this section if you wish to give permission for assessment	
I have read the Children and Young People Continuing Care Information leaflet and had opportunity to ask questions as needed. I/we the undersigned, give permission for NHS Dudley CCG to undertake an assessment of my child/young person's healthcare needs and for subsequent assessments and information sharing as appropriate to determine eligibility to receive NHS funded care.	
Signature:	Contact Telephone No:
Date:	
Signature:	Contact Telephone No:
Date:	

Children and Young People's Continuing Care Assessment

Pathway for Children and Young People's Continuing Care

It is essential that any consideration for the Continuing Care service to become involved is performed via a Multi-Disciplinary Team meeting in the first instance

Process



Abbreviations

CCA	Continuing Care Assessment (assessment carried out to establish the needs a child or young person has, at that moment in time).
CAMHS	Child and Adolescent Mental Health Service
CCG	Clinical Commissioning Group (*clinically*-led statutory NHS bodies responsible for the planning and *commissioning* of health *care* services in their local area)
CYPCC	Children and Young Person's Continuing Care
DIHC	Dudley Integrated Health and Care Trust
DST	Decision Support Tool (the tool that is used within the process to assess needs)
EHCP	Education Health Care Plan (the plan for children and young people aged up to 25 who need more support than is available through special educational needs support. This plan identifies the educational, health and social needs that are required and sets out the additional support to meet those needs)
LAC	Looked After Child
MDT	Multi-Disciplinary Team (group of professionals who provide support to child/young person and to parents)
OT	Occupational Therapist
SEND	Special Educational Needs and Disabilities
TAC	Team around Child (another way of saying multi-disciplinary team)

ASSESSMENT, RECOMMENDATION AND DECISION

SECTION 1: PERSONAL DETAILS, BACKGROUND, REFERRAL

Family Name:		Given Name(s):		
DOB		Gender	Female	Male
Ethnicity		Language		
Advocacy required?	Yes / No	Is an interpreter needed?	Yes / No If Yes, what language?	
NHS Number		Social Worker		
		Social Care Number		
Family Address (including e-mail)		Current Address (if different)		
Post Code		Post Code		

Family Members/Significant Others/Contacts		
Name	Relationship	Contact Details
Supportive Extended Family		

Emergency Contact Name	Telephone
GP:	**Responsible CCG:**

GP Practice:	
Address:	
Telephone:	

Child in Care	Yes	No	If yes, date of last health review:		
If YES by which Local Authority and which section:					
Who has parental responsibility?					
EDUCATION					
School:			Child/young person subject to SEN Assessment and has an Educational, Health and Care Plan?	Yes / No	If Yes, Case Officer details:
			School/Education contact person:		
			Tel:		
Post code			E-mail		
CURRENT SUPPORT TO CHILD/ FAMILY					
Agency			Type of Support		

CONSENT				
Please obtain verbal and signed consent *(This referral cannot be accepted without consent)*	**Child / Young Person**		**Parent / Carer**	
Are they aware that a referral has been made and consented to the sharing and obtaining of information to support this application? *(delete as appropriate)*	Yes	No	Yes	No

Have parents/carers been involved/contributed to the completion of this checklist? *(delete as appropriate)*	Yes	No	Yes	No
Has the signed consent form been attached to the application – please highlight the answer if the form has been typed? *(this will be required to proceed)*	Yes	No	Yes	No

Are there any agencies that parents do not want to be referred to within this pre-assessment?	

Parent/Carer signature/s (or those with parenting responsibility) and names printed in full

	Signature	Print name	Date
4.			
5.			
6.			

Child/Young Person's signature and name printed in full (if applicable)

Signature	Print name	Date

Date of Assessment (CCA/DST):		**Date Pre-Assessment Checklist completed and received:**	
REFERRERS CONTACT DETAILS			
Name	Address		

Telephone		Email	
NHS Health Professional details (completing form) *Please note you (or a representative) will be expected to support at all reviews to ensure clinical oversight continues, as per the health commissioned service specification.			
Name	Address		
Telephone		Email	
PD Physical disability	LD Learning disability	MH Mental health	Palliative/EOL End of life care

SECTION 2: SUMMARIES

HEALTH
Please summarise the health needs of the child/young person with details of any diagnoses and provision. Additional health information will be required in the Decision Support Tool section. The activities of daily living/24-hour care diary are optional submissions that might assist the assessment process.

SOCIAL CARE
Please provide a summary below of the child or young person's social care needs with details of any arrangements in place i.e. social care package. This could include short break provision, housing arrangements, transport, recreation and leisure. Please also indicate if a social care assessment has taken place.

EDUCATION

Please provide any relevant information regarding the child or young person's educational needs. What additional support or reasonable adjustments are required in that setting?
Have the relevant sections of the EHCP been completed in relation to health strengths and needs, outcomes and health provision: Section C, E and G

RISK ASSESSMENTS
Please provide a summary of any risks (to child/young person or others) resulting from health needs, including any information regarding the frequency, unpredictability, deterioration and instability of health needs. ***please provide relevant risk assessments**.

EXISTING ASSESSMENTS

Provide details below of any relevant **assessments or reports completed in the last 12 months** *(e.g. Education, Health and Care Plan or Statement of SEND, CAMHS assessments, child protection plan/early help plan)*. These will be referenced in relation to the level of needs within health domains, or copies will be required as needed.

HEALTH		EDUCATION		SOCIAL CARE	
	CAMHS assessment		EHC Plan		Child in Need
	OT assessment		Educational Psychology		Child in Care
	Physio assessment		School targets		Child Protection
	SALT assessment		School report		Early Help

Looked After Child (documents for review purposes in reference to children/young people who are placed by Local Authority and in receipt of Continuing Care support). These will be required to perform the annual CCA.

	Compliance review
	Independent Review (by Independent reviewing Officer)
	Annual health review (Looked After Children's Nurse)
	EHCP annual review

OTHER:

SECTION 3: PREFERENCES

PREFERENCES AND VIEWS OF CHILD/ YOUNG PERSON			
Did the child/young person contribute to their assessment? Yes / No			
If no please indicate why not:			
Were the views of the young person provided/facilitated by a representative? Yes/ No			
If yes who acted as the representative and what is their status?			
Name	Address	Contact Details	Status
Views and aspirations of the child or young person and their family • The child/young person's issues, concerns, anxieties • The child/young person's preferences about care delivery • The family's preferences about care delivery			
SUMMARY OF VIEW/ PREFERENCES OF CHILD/ YOUNG PERSON/ PARENTS/ CARERS			

Details of Child/ Parent/Carer providing information.		
Name	Relationship to Child/ Young Person	Contact details

SECTION 4: Decision Support Tool

The Multi-Disciplinary Team (including young person and family where appropriate) should complete the CCA indicating the level of need.

Please provide the relevant reports/assessments to show what support/management is needed with regards to the level of need identified, if no needs are indicated then please state N/A.

It is important to have the relevant supporting information to understand what health needs are being met by universal and specialist commissioned services, and what the child or young person's unmet need is.

BREATHING	
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

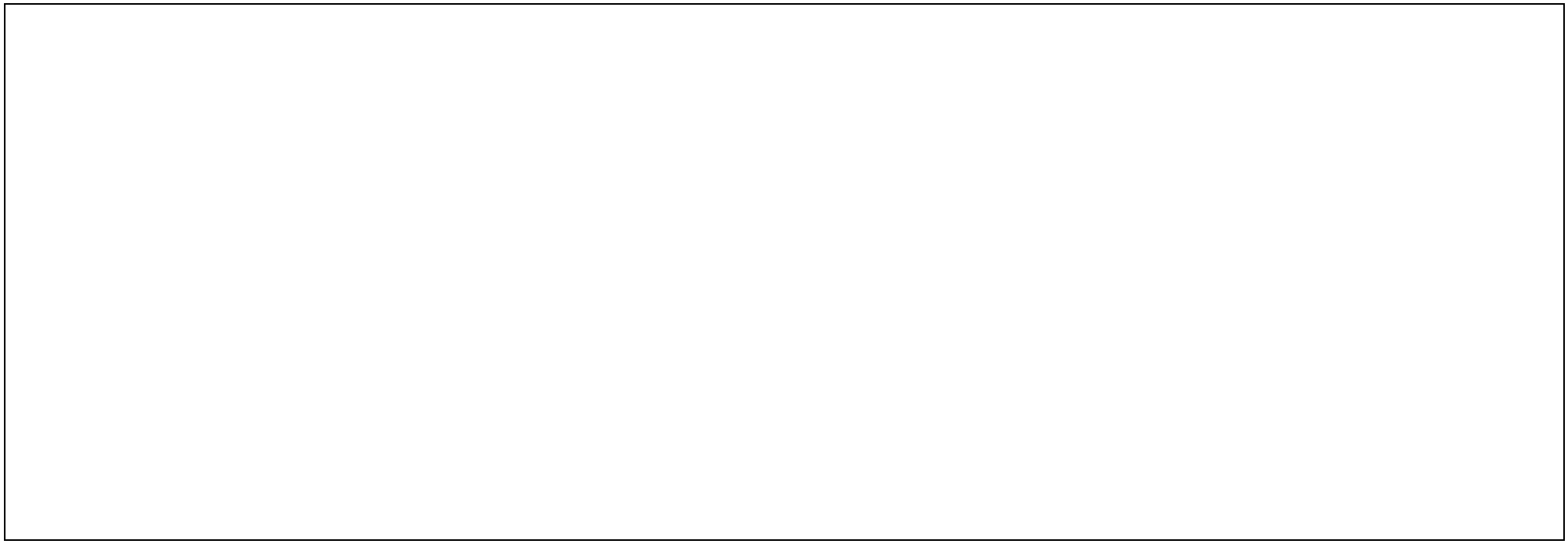
Requires high flow air / oxygen to maintain respiratory function overnight or for the majority of the day and night; **or** is able to breath unaided during the day but needs to go onto a ventilator for supportive ventilation. The ventilation can be discontinued for up to 24 hours without clinical harm; **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** 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.	Severe
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.	Priority

Describe the Child or Young Person's specific needs relevant to this domain

EATING AND DRINKING	
Description	**Level of need**
Able to take adequate food and drink by mouth, to meet all nutritional requirements, typical of age.	No additional needs

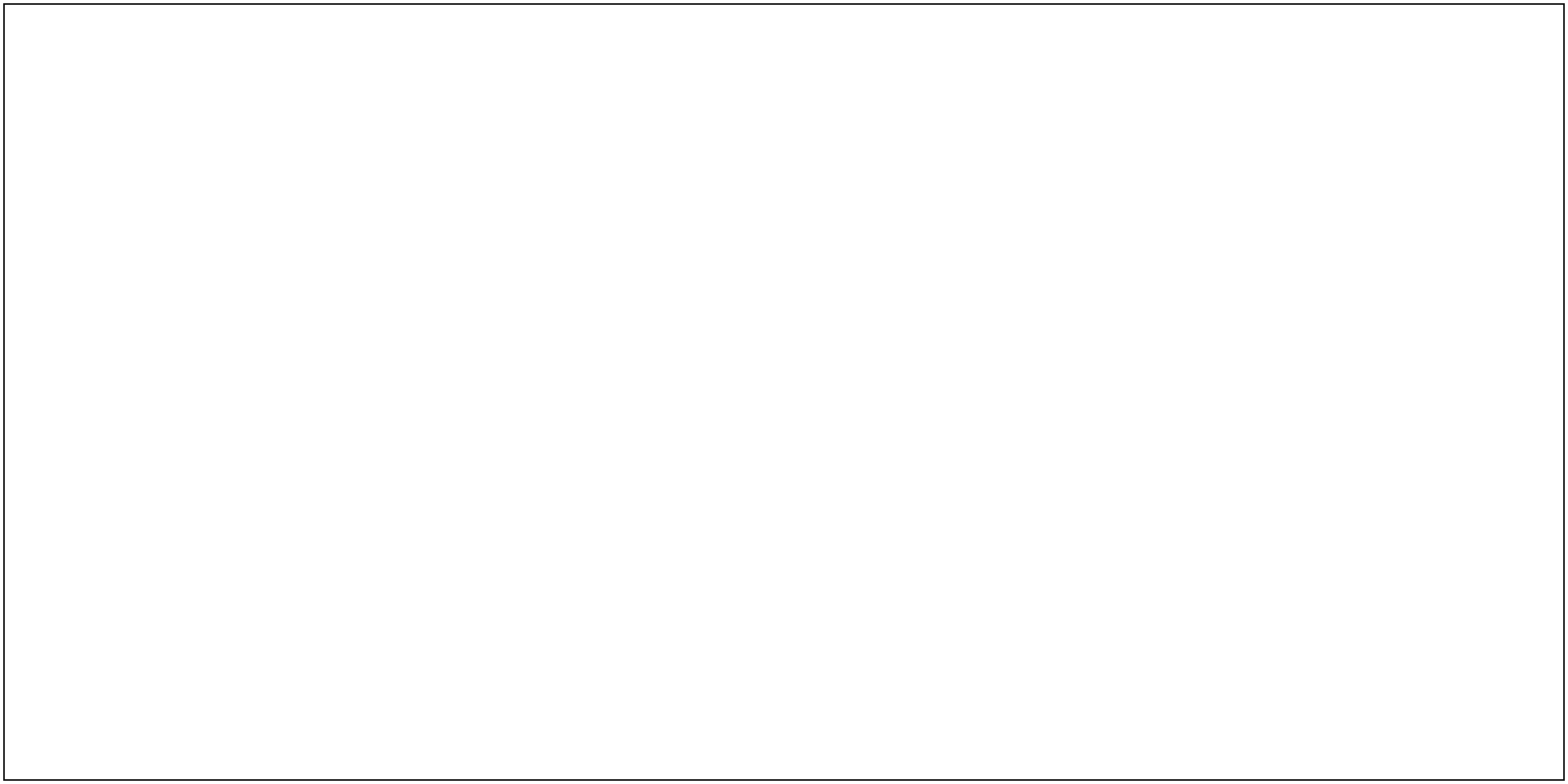
Some assistance required above what is typical for their age; **or** needs supervision, prompting and encouragement with food and drinks above the typical requirement for their age; **or** needs support and advice about diet because the underlying condition gives greater chance of non-compliance, including 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.	Low
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.	Moderate
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.	High
The majority of fluids and nutritional requirements are routinely taken by intravenous means.	Severe

Describe the Child or Young Person's specific needs relevant to this domain



MOBILITY	
Description	**Level of need**
Mobility typical for age and development.	No additional needs
Able to stand, bear their weight and move with some assistance, and mobility aids. **or** moves with difficulty (e.g. unsteady, ataxic); irregular gait.	Low
Difficulties in standing or moving even with aids, although some mobility with assistance. **or** 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; **or** 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.	Moderate
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; **or** at a high risk of fracture due to poor bone density, requiring a structured management plan to minimise risk, appropriate to stage of development; **or** involuntary spasms placing themselves and carers at risk; **or** extensive sleep deprivation due to underlying medical/mobility related needs, occurring every one to two hours (and at least four nights a week).	High
Completely immobile and with an unstable clinical condition such that on movement or transfer there is a high risk of serious physical harm; **or** positioning is critical to physiological functioning or life.	Severe

Describe the Child or Young Person's specific needs relevant to this domain



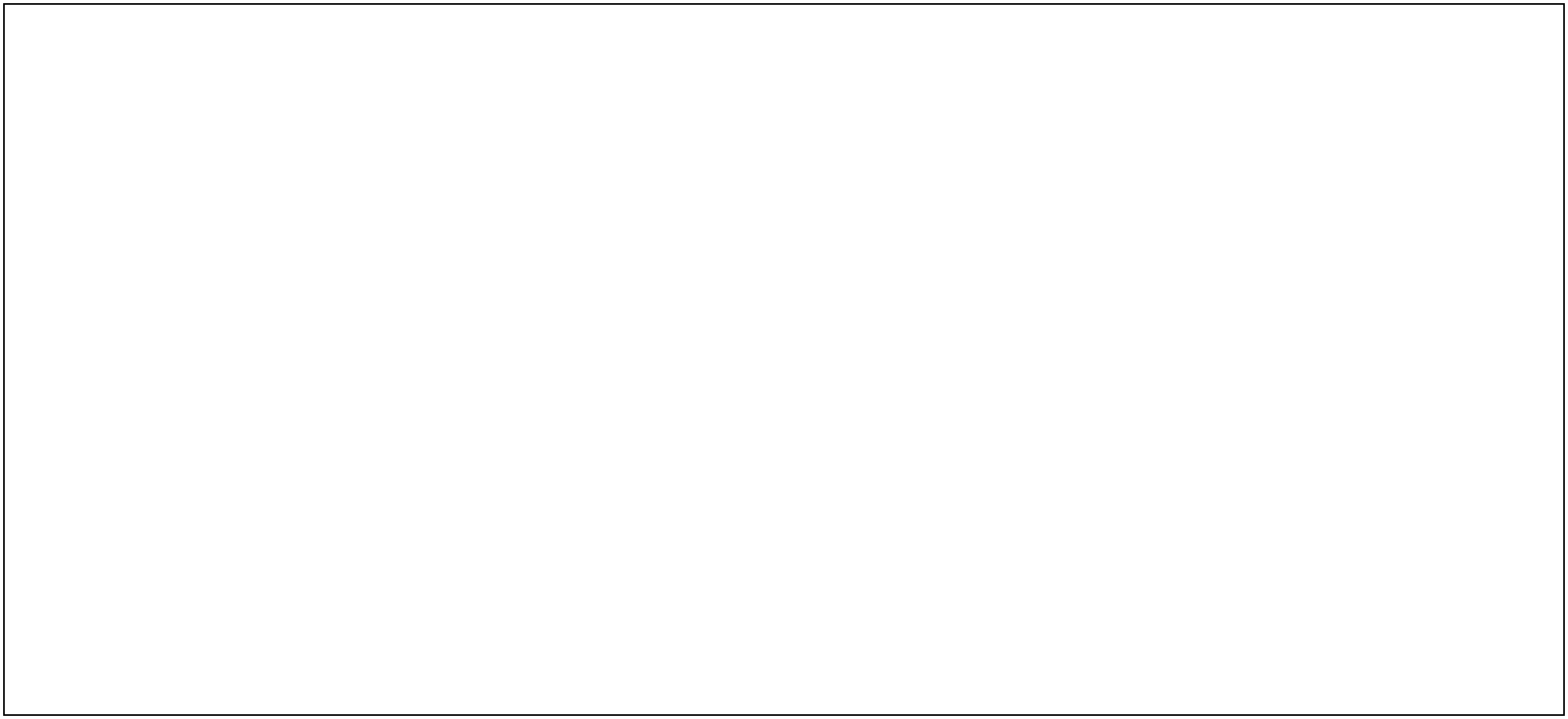
CONTINENCE AND ELIMINATION	
Description	**Level of need**
Continence care is routine and typical of age.	No additional needs
Incontinent of urine but managed by other means, for example, medication, regular toileting, pads, use of penile sheaths; **or** is usually able to maintain control over bowel 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

Describe the Child or Young Person's specific needs relevant to this domain

SKIN AND TISSUE VIABILITY	
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

Describe the Child or Young Person's specific needs relevant to this domain



COMMUNICATION	
Description	**Level of need**
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.	No additional needs
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. Family/carers may be able to anticipate needs through non-verbal signs due to familiarity with the individual.	Low
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. **or** support is **always** required to facilitate communication, for example, the use of choice boards, signing and communication aids. **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.	Moderate
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.	High

Describe the Child or Young Person's specific needs relevant to this domain

DRUG THERAPIES AND MEDICATION	
Description	**Level of need**
Medicine administered by parent, carer, or self, as appropriate for age.	No additional needs
Requires a suitably trained family member, formal carer, teaching assistant, nurse or appropriately trained other to administer medicine due to • age • non-compliance • type of medicine; • route of medicine; and/or • site of medication administration	Low
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; **or** monitoring because of potential fluctuation of the medical condition that can be non-problematic to manage; **or** sleep deprivation due to essential medication management – occurring more than once a night (and at least twice a week).	Moderate
Drug regime requires management by a registered nurse at least weekly, due to a fluctuating and/or unstable condition; **or** sleep deprivation caused by severe distress due to pain requiring medication management – occurring four times a night (and four times a week). **or** requires monitoring and intervention for autonomic storming episodes.	High
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; **or** extensive sleep deprivation caused by severe intractable pain requiring essential pain medication management – occurring every one to two hours **or** requires continuous intravenous medication, which if stopped would be life threatening (e.g. epoprostenol infusion).	Severe
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.	Priority

Describe the Child or Young Person's specific needs relevant to this domain

PSYCHOLOGICAL AND EMOTIONAL	
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; **or** 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).	Moderate
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; **or** 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.	High

Describe the Child or Young Person's specific needs relevant to this domain

SEIZURES	
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

Describe the Child or Young Person's specific needs relevant to this domain

CHALLENGING BEHAVIOUR	

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 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

Describe the Child or Young Person's specific needs relevant to this domain

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

Assessed Levels of Need

Care Domain	**N**	**L**	**M**	**H**	**S**	**P**
Breathing						
Eating and drinking						
Mobility						
Continence or Elimination						
Skin and Tissue Viability						
Communication						
Drug Therapies and Medicines						
Psychological and Emotional Needs						
Seizures						
Challenging Behaviour						
Totals						

Children and Young People's Continuing Care

Resource Allocation Tool

Child/Young Person

Name:

DOB:

NHS Number:

Assessment/review date:

Continuing Care Panel date:

RATIONALE	
Intensity	
Severity	
Complexity	
Risk	

DST DOMAINS AGREED AT PANEL						
	Priority	Severe	High	Moderate	Low	No Needs
Breathing	60	40	25	10	2	0
Eating & Drinking		6	4	2	1	0
Mobility		4	3	2	1	0
Continence or Elimination		4	3	2	1	0
Skin & Tissue Viability		4	3	2	1	0
Communication			6	4	2	0
Drug Therapies & Medication	6	4	3	2	1	0
Psychological & emotional needs			3	2	1	0
Seizures		10	5	3	1	0
Challenging Behaviour	5	4	3	2	1	0
TALLY						

CONTINUING HEALTHCARE PANEL OUTCOME	
Agree eligibility (complete RAT)	
Decline eligibility (Inform Referrer and parents of panel decision)	
More information required	

SUPPORT NETWORKS	
Identify all additional support networks that apply and deduct from total.	
➢ No support networks	**0**
➢ Social Care Direct payments	**1**
➢ Overnight Residential Short Breaks	**2**
➢ ACORNS Grant nights	**2**
➢ School/Nursery <20 hours per week	**3**
➢ School/Nursery >20 hours per week	**4**

Diagnosis specific to breathing domain only i.e CCHS or where breathing need is the only domain to determine eligibility	
Severity of diagnosis as per Consultant	**Allocation** **(automatic allocation, RAT not utilised)**
MILD	5 nights (50 hours per week)
MODERATE	6 nights (60 hours per week)
SEVERE	7 nights (70 hours per week)

Resource Allocation Tool	Score
DST	
BREATHING	
EATING AND DRINKING	
MOBILITY	
CONTINENCE AND ELIMINATION	
SKIN AND TISSUE VIABILITY	
COMMUNICATION	
DRUG THERAPIES AND MEDICATION	
PSYCHOLOGICAL AND EMOTIONAL NEEDS	
SEIZURES	
CHALLENGING BEHAVIOUR	
SUB-TOTAL	
Support Network (to be deducted from total)	
TOTAL	

CONTINUING CARE HOURS	
SCORE	**HOURS PER WEEK**
0-10	0-2
10-15	2-5
15-20	5-10
20-25	10-20
25-30	20-25
30-35	25-30
35-40	30-35
40-45	35-45
45-50	45-60
50-60	60-80
60-70	80-100
70-80	100-115
80-95+	115-120+

Recommendations to Commissioning Manager C/YP & Families
Continuing care eligibility is subject to regular reviews and of the child/young person's assessed health needs.

Outcome	
Clinical Commissioning Manager: CYP Complex Care	**Date**

Continuing Care
Transition Notification Form

Young person's details					
Name:					
Date of birth:		**Age:**		**NHS Number:**	
Address:					
Gender (delete as appropriate)	**MALE/FEMALE**	**Ethnicity:**			
		Religion:			
First language (if not English)		**Translator needed:**			
		Other communication support needed:			
Parent/Carers name:		**Parent/Carers name:**			
Contact no:		**Contact no:**			
NB. details of one parent only are acceptable, but it must be the parent with responsibility.					
If parental responsibility is not held by parents					
Parental responsibility held by:		**Contact no:**			
		E-mail:			
Basis of parental responsibility: (e.g. legal guardian, LA section 20 etc.)		**Address:**			

GP: **Contact:**	**Social Worker:** **Contact :**
Community Nurse: **Contact:**	**School Nurse:** **Contact:**

Consent					
	Young Person			**Parent / Carer**	
Have they consented to being brought to the attention of the Adult Continuing Healthcare Team and for the sharing and obtaining of information in relation to the transition process? (delete as appropriate).	Yes	No	N/A	Yes	No

Medical History (and responsible Consultants)
Provide a brief summary below of the young person's primary health needs, with details of any diagnoses and provision.

Social Care
Provide a brief summary below of the young person's social care needs with details of any arrangements in place. (including direct payments/short breaks)

Education	
Name of school or college attending	
Year group	
Contact details (where known)	
What additional support or reasonable adjustments are required in that setting?	
Does the young person have special educational needs?	

Doe the young person have an EHCP?			
Yes		Date of issue/review:	Copy enclosed?
No		If No: state reason why	

Notification Date:			
Sent by:		**Signature:**	
Designation:			

Children and Young People's Continuing Care
Personal Health Budget: Expression of Interest Form

CHILD OR YOUNG PERSON'S DETAILS								
Name:								
Date of birth:		**Age:**		**NHS Number:**				
Address:								
GP Name/Address:								
Ethnicity:		**Religion:**						
Gender (delete as appropriate)	**MALE/FEMALE**	**Language:**						
		Interpreter required?			**Yes**	**Language:**		**No**
Parent/Carers name:		**Parent/Carers name:**						
Contact no:		**Contact no:**						
NB: Details of one parent only are acceptable, but it must be the parent/carer with responsibility.								
Date of Continuing Care Assessment/Review:								
Does the Child/Young Person have an EHCP?								
Yes		**Date of issue/review:**		**Copy enclosed?**				
No		**If No: state reason why**						

EXPRESSION OF INTEREST

I/we wish to express an interest in having a Personal Health Budget. I/we understand that under the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) (Amendment) Regulations 2013, I/we have a 'right to have' a personal health budget, covering the part of the care package which would be provided by the NHS.

SIGNATURES: (Persons signing this form must have parental responsibility)		
Name:	**Signature:**	**Relationship to Child/Young Person**

Please send this form to:

Allison Stuchfield – Nurse Assessor for Children and Young People's Continuing Care

Dudley IHC, 2nd Floor, Brierley Hill Health and Social Care Centre, Venture Way, Brierley Hill, DY5 1RU

Children and Young People's Continuing Care Fast Track

Child or young person's details			
Name:			
Date of birth:		**NHS Number:**	
Address:			
Current Location:			
Date of Discharge: (if applicable)			
Discharge Location: (if applicable)			
Gender: (delete as appropriate)	**MALE/FEMALE**	**Ethnicity:**	
First language: (if not English)		**Translator needed: No/Yes**	
		Other communication support needed:	
Mother's name:		**Father's name:**	
Contact no:		**Contact no:**	
NB. details of one parent only are acceptable, but it must be the parent with responsibility.			
If parental responsibility is not held by parents			
Parental responsibility held by:		**Contact no:**	
		E-mail:	
Basis of parental responsibility (e.g. legal guardian, LA section 20 etc.)		**Address:**	
GP: **Contact:**		**Social Worker:** **Contact :**	
Brief description of illness/condition:			

End of Life Care Criterion
The child or young person named in this referral fulfils the criteria where by End of Life care is deemed appropriate and written supportive evidence outlining the presenting needs and short life expectancy has been documented by a named Consultant.

Children's Continuing Care Panel	
Decision-	Agree/Disagree
Recommendation	
Rationale	
Package to be reviewed in 1 2 3 4 5 6 weeks/months	
Signature of Chair on behalf of members:	
Date:	