National Framework for Children and Young People’s Continuing Care

Decision Support Tool

2016

 **October 2016**

Decision support tool for children and young people.

The Decision Support Tool for children and young people is intended to bring assessment information together in a concise, consistent way. It is designed to help ensure that all relevant needs are assessed and captured. A Word® version of the Tool is also available which can be used as a template locally.

The Tool is not stand-alone. The nominated children and young people’s health assessor will have worked alongside a multi-agency or multidisciplinary team to compile the information required to complete the Tool, drawing on the three key areas of assessment already mentioned:

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

The nominated children and young people’s health assessor should use the Tool to match, as far as possible, the child/young person’s level of need with the relevant description. This approach should build up a detailed analysis of individual needs, in a family context, and also provide evidence to inform the provision of a package of continuing care. The tool is not prescriptive, and evidence-based professional judgement should be exercised in all cases to ensure that the child or young person’s overall level of need is correctly assessed.

This process and the information collected will provide the basis for recommendations to be presented to the multi-agency decision-making forum; this will inform the decision on whether or not a package of continuing care is needed.

The Decision Support Tool sets out children’s needs across 10 care domains, divided into different levels of need:

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

The nominated children and young people’s health assessors will use their clinical skill, expertise and evidence-based professional judgement to consider what, for each care domain, is over and above what would be expected for a child or young person of that age. For example, incontinence would only become recognised as an issue when a child or young person has continence needs beyond those typical for their age.

The needs described in the care domains and levels of need in the Tool may not always adequately describe every child or young person and their family’s circumstances. Professional judgement and clinical reasoning are paramount in ensuring that a child or young person’s needs are accurately assessed, taken into account and given due weight when making a decision regarding their continuing care needs. All four parts of the assessment process interact in defining the child or young person’s overall need for continuing care.

There may be circumstances where a child or young person may have particular needs which do not fall within the 10 care domains described in the Tool. Examples might include a child who has cancer, or who is unable to regulate their body temperature, or who has an unstable cardiac condition.

Information on these needs should of course be included as evidence in the assessment if considered significant, usually drawn from risk assessments or professional reports. Some significant health needs may not of course result in a need for continuing care, if they are already supported by outpatient or other services routinely commissioned. Some needs may not fall within the domains, but may still be reasonable to meet, and the commissioner must consider these requests, on a case by case basis.

The assessment of the level of need must recognise that where a child or young person requires constant supervision or care which is largely provided by family members, there will be a need for professional support to allow the family time off from their caring responsibilities, and this may require a social care assessment, and agreement, between the CCG and the local authority (which is usually the commissioner of respite care), of the respective contribution.

The Tool provides a framework for reaching a decision on levels of need. Information will need to be organised and documented to support that. Some suggested prompts are included. Note that questions may not necessarily be answerable in chronological order, and we have tried to avoid questions which would be more for a social care assessments (some questions on family circumstances have however been included). More than one section may correspond with a statutory section in an EHC plan. In every section, assessment should seek to identify needs **met and unmet**, and current need, rather than past or anticipated need.

Child and family details

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| **Child / young person** |
| **Child’s name** |  |
| **Date of birth**  |  |
| **NHS Number**  |  |
| **Address** |  |
| **Telephone number**  |  |
| **E-mail**  |  |
| **Mother/first parent’s name** |  |
| **Father/second parent’s name** |  |
| **First language**  |  |
| **Communication** * *Is an interpreter needed?*
* *How can professionals best communicate with the child*?
 |  |
| **Date referred for assessment** | Click here to enter a date. |
| **Date of pre -assessment**  |  Click here to enter a date. |
| **Referred by***Give referring professional and provider organisation and relevant contact details* |  |
| **Responsible CCG** * *GP practice of registration*
* *CCG of which the child or young person’s GP is a member*
 |  |
| **Assessment start date:*** *Clock starts on the day of the assessment (Nb. A decision should ideally be made within 6 weeks of the commencement of assessment.)*
 |  Click here to enter a date. |
| **Family circumstances** |
| **Family support** – **prompts to consider if appropriate*** *What kind of help is available in the family’s circle of friends and relations?*
* *Does any other member of the family have health or care needs?*
* *Are siblings involved in care provision?*
* *Are there any other organisations or groups that support the family/carer’s family?*
* *Summary of parents’/carer’s occupation, employment/shift patterns.*
* *Effect of the child/young person’s condition on the parent/carer’s ability to work.*
* *Has a social care assessment been made*
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| **Housing** * *Adequacy for the child’s/family’s/carer’s family’s needs?*
* *Any adaptations required?*
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| **Transport** * *Is the family/carer’s family reliant on public transport?*
* Are there particular difficulties in transportation (is the child receiving a mobility component of disability Living Allowance)?
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| ***Recreation and leisure**** *Is the child/young person able to choose leisure activities?*
* *What is required to enable the child/young person to access leisure activities?*
* *What are their interests or hobbies?*
* *Are the recreational needs of siblings and other family/carer’s family members being met?*
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Education and learning

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| **Education** |
| **Name of nursery, school or college attending*** *Is the child/young person able to access an appropriate educational setting, either full or part-time?*
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| **Special Educational Needs*** *Do they have a statement of Special Educational Need or an Education, Health and Care Plan?*
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| **Education and learning** * *What additional support or reasonable adjustments are required in that setting?*
* *If the child/young person is too ill to access a setting, what other provision is in place to ensure continuity of learning?*
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This first section should also of course include the views and aspirations of the child or young person and their family – this is the major element of Section A of the EHC plan, and should have a correspondingly prominent position in any continuing care assessment. Ideally this section should consider:

* The child/young person’s issues, concerns, anxieties.
* The child/young person’s preferences about care delivery.
* The family’s preferences about care delivery

Team around the child

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| **Professionals involved** |
| **Name, telephone number and location of the following where relevant:**

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| --- | --- |
| * Registered GP
* all consultants
* Designated Medical or Health Officer for SEND
* Community Paediatrician
* Psychologist
* Psychiatrist
* Community Children’s Nurse
* Specialist Nurse (e.g. for epilepsy).
* Nurse consultant
* Interpreter
 | * CAMHS nurse
* Named ward nurse
* Health Visitor
* School Nurse
* District Nurse
* Social Worker
* Occupational Therapist
* Speech and Language Therapists
* Physiotherapist
* other therapists
* SENCO
* Short break services
* Lead Professional
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| **Please list the assessments and other key evidence that were taken into account in completing the DST, including the dates of the assessments:** |
|  |
| **Clinical details** |
| **Medical history*** *Dates of significant health events/current health status.*
 |  |
| **Equipment – permanent or disposable**• *Details (this might include the type of equipment, supplier, maintenance arrangements etc.)*  |  |
| **Treatment / care needs** * *Interventions; who provides and monitors the service; care plans.*
* *Symptom management and pain control.*
* *What is the 24-hour daily care routine?*
* *How are the child/young person and family/carers supported?*
* *Does the family have adequate information on the child/young person’s condition/future?*
* *Competencies required to care for the child/young person.*
* *Is there a lead professional, and is this working well?*
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| **Emotional and support needs**  |
| Assessment should consider the emotional support needs of a child, young person and their family. * *What is the effect of the child/young person’s condition on each member of the family?*
* *What times of the day/events are stressful?*
* *How does the family cope?*
* *Who does the family call on for support at these times?*
* *Are there times when the child or young person need particular support?*
* *How do they communicate as a family?*
* *What is the child/young person’s understanding of his/her condition?*
* *What understanding do siblings have of the child/young person’s condition?*
* *Is an assessment by the child and adolescent mental health service required?*
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Outcomes

The assessment of a child’s continuing care needs must consider the outcomes necessary to enable the child or young person to get the best from life, and outcomes relating to transition (where the child is 14 years or older).

They should be specific, deliverable and linked directly to the child’s wishes. They should include where appropriate, outcomes for transition, through key changes in a child or young person’s life, such as changing schools, moving from children’s to adult care and/or from paediatric services to adult health, or moving on from further education to adulthood.

Key issues would include:

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| * Maintaining a safe environment.(including vulnerability to exploitation)
* Communicating.
* Breathing.
* Eating and drinking.
* Elimination.
* Personal cleaning and dressing.
* Controlling body temperature.
* Mobilising.
 | * Leisure
* Learning.
* Expressing individuality.
* Sleeping.
* Employment
* Independence
* Further education
* Emergency care
* End of life.
* Pain management
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Interpreting the level of need using the domains

Health assessors should consider the needs of the child or young person across the following 10 domains of care. Care has been taken to avoid duplicating needs in two separate domains. However, assessors should consider how different but inter-related needs across more than one domain can complicate the child or young person’s overall care needs and result in sufficient complexity, intensity or risk to demonstrate continuing care needs.

In each domain, a number of different descriptors are given, separated by or; this does not necessarily prevent more than one descriptor being relevant to the child or young person’s needs. It is essential that clear evidence is obtained to support assessments in the relevant domains, and that this evidence is recorded as part of the continuing care assessment, and included in any subsequent care plan.

In order to help with interpretation, some examples have been included to clarify certain types of need, although these have been used sparingly. However, the fact that a child has a condition or symptom which is mentioned is not in itself an indicator of the level of need (for example, the fact that a child has a tracheostomy does not automatically mean they have a Priority need under the Breathing domain).

A child is likely to have continuing care needs if assessed as having a severe or priority level of need in at least one domain of care, or a high level of need in three domains of care.

The level of need in a single domain may not on its own indicate that a child or young person has a continuing care need, but will contribute to a picture of overall care needs across all domains. Levels of need are relative to each other as well as to those in other care domains. It is not possible to equate a number of incidences of one level with a number of incidences of another level – that needs assessed as ‘moderate’ in two domains are the equivalent of one ‘high’ level of need, for example. In presenting recommendations to a multi-agency forum, nominated children and young people’s health assessors should consider the level of need identified in all care domains in order to gain the overall picture.

Nominated children and young people’s health assessors should be mindful that even if the child or young person is assessed as not having continuing care needs, they may require other healthcare input from universal services or community children/young person’s nursing or other specialist services.

An assessment may identify behaviours under Challenging behaviour which cannot be met by health services or which would be more appropriately met by special educational support, or social care. In such cases, there should be a dialogue with the local authority, and if necessary, agreement of a joint package of care, in line with respective commissioning policies. Where a child has a Statement of SEN or an Education, Health and Care plan, there may of course be a pre-existing package of educational support which requires no additional support from health or social care services. It is preferable that the assessment gives an honest appraisal of a child or young person’s needs, to be followed by a discussion as to who provides the necessary support, than that the assessment attempts to pre-empt this, and ignores potentially relevant evidence.

## Breathing

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| **Describe the child or young person’s specific needs relevant to this domain.**  |
| Prompts: * Is Breathing typical of age and development
* Does the child/Young person have an artificial airway
* Does the child/young person have a manageable airway?
* How often are interventions needed?
* Does the child/young person have a history of apnoea?
* Does the Child/young person have breathing difficulties that require intervention?
* Does the child/young person require oxygen and to what intensity?
* What other interventions are required? i.e. suctioning, cough assist, antibiotic therapy, nebulisers
* Any admissions to hospital for chest problems within the past 12 months – any lasting impact i.e. increase in ventilation needs/now requires BiPAP overnight?
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**Breathing - assessors should indicate the level of need**

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| **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 or supported 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 |

## Eating and drinking

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| **Describe the child or young person’s specific needs relevant to this domain.**  |
| **Prompts:** * Is the child/young person to take adequate food and drink by mouth, to meet all nutritional requirements, typical of age.
* Does the child/young person require any assistance to eat/drink?
* Is the child/young person at risk of aspiration?
* Does the Child/young person have the input of a dietician and a feeding plan?
* Does the child/young person require enteral feeding?
* Have there been any problems with weight control/growth as a result of poor dietary intake?
* Are there factors that affect the intake of diet and fluids such as mood/chest infections/neurological disorder such as Autism/ADHD?

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**Eating and drinking – assessors should indicate the level of need**

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| **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 |

**Mobility**

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| **Describe the child or young person’s specific needs relevant to this domain.**  |
| Prompts: * Is mobility typical for age and development?
* Is the child/young person’s mobility appropriate for their developmental age?
* Does the child/young person have a set therapy plan?
* What level of supervision and number of people required assisting with mobility?
* Describe the frequency of interventions required.
* Are there any factors that impact on safe mobility/transfer i.e. spasms/pain etc.
* Does the child/young person have any equipment to assist safe moving and handling?

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## **Mobility -** assessors should indicate the level of need

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| **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 |

## Continence or elimination

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| **Describe the child or young person’s specific needs relevant to this domain.**  |
| **Prompts*** Is continence care routine and typical of age
* Is continence appropriate for developmental age?
* What Level of assistance/intervention is required?
* Does the child/young person require prescribed medication?
* Does the child/young person have any condition that impacts on elimination i.e. short bowel syndrome/milk intolerances/ what impact does this have on care?
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**Continence or elimination - assessors should indicate the level of need**

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| **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 askilled practitioner or trained carer;**or**intermittent catheterisation by a trained carer or care worker;**or**has a stoma that needs extensive attention every day.**or** requires haemodialysis in hospital to sustain life. | High |
| Requires dialysis in the home to sustain life. | Severe |

## Skin and tissue viability

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

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| **Describe the child or young person’s specific needs relevant to this domain.**  |
| **Prompts:** * Describe any evidence of wounds or skin conditions that should be given a tissue viability assessment or require intervention.
* Is any specialist equipment required to maintain healthy skin?
* Are any creams/lotions used to prevent dryness/sores/cracking – how often is this applied?
* Is the child/young person prone to bruising/bleeding?
* Can the child/young person move independently? How often is their position changed and how many people are needed to achieve this?
* Has there been any deterioration of the skin condition as a result of infection/over granulation?
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**Skin and tissue viability - assessors should indicate the level of need**

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| **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**open wound which is responding to treatment**or**has a tissue viability plan which requires regular review.  | Low |
| Active skin condition requiring a minimum of weekly reassessment and which is responding to treatment;**or**high risk of skin breakdown that requires preventative intervention from a skilled carer several times a day, without which skin integrity would break down;**or**high risk of tissue breakdown because of a stoma (e.g. gastrostomy, tracheostomy, or colostomy stomas) which require skilled care to maintain skin integrity.  | Moderate |
| Open wound(s), which is (are) not responding to treatment and require a minimum of daily monitoring/reassessment;**or**active long-term skin condition, which requires a minimum of daily monitoring or reassessment;**or**specialist dressing regime, several times weekly, which is responding to treatment and requires regular supervision. | High  |
| Life-threatening skin conditions or burns requiring complex, painful dressing routines over a prolonged period.  | Severe |

## Communication

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| **Describe the child or young person’s specific needs relevant to this domain.**  |
| Prompts:* Is the child/young person’s communication appropriate to developmental age?
* Describe any concerns with vision hearing or speech.
* Does the child/young person have the input from SALT?
* Does the child young person require any communication aids? What is used?
* Describe how parents/carers identify care needs
* Is the child/young person able to make choices know? How is this done?
* Has the child/young person had any ear infections/grummets inserted?
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**Communication - assessors should indicate the level of need**

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| **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 |

## Drug therapies and medication

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| **Describe the child or young person’s specific needs relevant to this domain.**  |
| Prompts: * Describe the medication the child/young person is prescribed and why
* Describe the child/young person’s compliance with medication
* Allergies?
* Does the child/young person require a suitability trained carer to administer medication?
* Last medication review? Were any changes made?
* Are any supplementary medications used? (these could be in the form of vitamins or over the counter medications/heat patches/herbal medications
 |

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

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|  **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 |

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

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| **Describe the child or young person’s specific needs relevant to this domain.**  |
| * Prompts:
* Describe child/young person’s mood disturbances or periods of anxiety or distress & the effects on their activities of living?
* Describe any measures that are taken to try to alleviate anxiety/distress and how effective this is
* Are any medication used? How effective are they?
* Are there any professionals involved i.e. CAMHS service and how frequently is this support accessed?
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**Psychological and emotional needs (beyond what would typically be expected from a child or young person of their age) – assessors should indicate the level of need**

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

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|  **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  |

## Seizures

|  |
| --- |
| **Describe the child or young person’s specific needs relevant to this domain.**  |
| Prompts: * Describe the child/young person’s type of seizure activity – how does this present, frequency, interventions required, recovery and impact on daily living
* Does the child/young person require emergency rescue medication and do they have an emergency plan?
* Has the medication recently changes and what impact has this had?
* Has the child/young person put on any weight recently and if so has this had an impact on seizure activity?
* Have there been any recent EEGs and what has been the outcome of this?
* What are the risks involved?
 |

**Seizures – assessors should indicate the level of need**

|  |  |
| --- | --- |
| **Description**  | **Level of need** |
| No evidence of seizures. | No additional needs |
| History of seizures but none in the last three months; medication (if any) is stable; **or**Daily generalised absences, occasional self-limiting (less than 15 minutes) focal seizures; **or**non-epileptic attacks / psychogenic non-epileptic seizures/ syncope. | Low |
| Daily self limiting (less than 15 minutes) focal seizures which require supervision to minimise the risk of harm; **or**frequent (more than two per month) nocturnal generalised tonic clonic seizures or cluster of three or more self-limiting (less than 5 minutes) generalised tonic-clonic seizures in 24 hours (more than twice per month).  | Moderate |
| Prolonged seizures (more than 5 mins for generalised tonic clonic seizures or more than 15 minutes for focal seizures) on at least a weekly basis or a cluster of 3 or more self-limiting (less than 5 mins) generalised tonic clonic seizures within a one hour period on a weekly basis;**or**an episode of status epilepticus (a generalised tonic clonic seizure ongoing after 30 minutes or focal seizure ongoing after 60 minutes - not including electrical status epilepticus in slow wave sleep or ESES), two to eleven times per year. | High  |
| Prolonged uncontrolled seizures (more than 5 minutes for generalised tonic clonic seizures or more than 15 minutes for focal seizures), occurring at least daily; **or**an episode of status epilepticus (a generalised tonic clonic seizure ongoing after 30 minutes or focal seizure ongoing after 60 minutes, not including ESES) once per month or more frequently.  | Severe |

## Challenging behaviour

|  |
| --- |
| **Describe the child or young person’s specific needs relevant to this domain.**  |
| Prompts: * Describe the child/young person’s behaviour patterns and how this is affected during daily routines.
* Does the child young person have aggressive or violent behaviour?
* Does the child young person express frustration around difficulties in communication?
 |

**Challenging behaviour – assessors should indicate the level of need**

Interpretation point: NICE use the following definition of challenging behaviour, taken from Eric Emerson, *Challenging behaviour: analysis and intervention in people with learning disabilities* (Cambridge University Press, Cambridge, 1995).

'Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.'

Note that the challenges of a health condition – relating to mobility for example – do not constitute challenging behaviour under this domain. However, a child or young person may exhibit challenging behaviour which serves a purpose for them related to their condition: ‘for example, by producing sensory stimulation, attracting attention, avoiding demands and communicating with other people.’

|  |  |
| --- | --- |
| **Description**  | **Level of need** |
| Functioning within current environment without unusual or frequent incidents of behaviour which challenges parents/carers/staff. Behaviour as expected for age or stage of development. | No additional needs  |
| Incidents of behaviour which challenge parents/carers/staff but which can be managed within mainstream services (e.g. early years support, health visiting, school).  | Low |
| Displays some challenging behaviours which are more frequent, more intense or more unusual than those that expected at their 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 |

## Assessed Levels of Need

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Care Domain**  | **P** | **S** | **H** | **M** | **L** | **N** |
| Breathing |[ ] [ ] [ ] [ ] [ ] [ ]
| Eating & Drinking |  |[ ] [ ] [ ] [ ] [ ]
| Mobility |  |[ ] [ ] [ ] [ ] [ ]
| Continence & Elimination |  |[ ] [ ] [ ] [ ] [ ]
| Skin and tissue viability |  |[ ] [ ] [ ] [ ] [ ]
| Communication |  |  |[ ] [ ] [ ] [ ]
| Drug Therapies and Medication |[ ] [ ] [ ] [ ] [ ] [ ]
| Psychological and Emotional Needs |  |  |[ ] [ ] [ ] [ ]
| Seizures |  |[ ] [ ] [ ] [ ] [ ]
| Challenging behaviour |[ ] [ ] [ ] [ ] [ ] [ ]
|  |  |  |  |  |  |  |
| **Totals** |  |  |  |  |  |  |

**Please note below any views of the child or young person and their family on the completion of the DST that have not been recorded above, including whether they agree with the domain levels selected. Where they disagree, this should be recorded below, including the reasons for their disagreement. Where the child or young person and their family is represented or supported by a carer or advocate, their understanding of the individual’s views should be recorded.**

|  |
| --- |
| This section may be used to cover anything else such as inability to control own body temperature, very poor sleeping habits and how this impacts on the child/young person and if this impacts on school attendance/participation.Blood glucose and/or ketone measuring – reason, frequency, what action is taken as a result of the outcome of the test? |

## Recommendation of the assessor filling in the DST

**Please give a recommendation on the next page as to whether or not the individual is eligible for Children and Young People’s Continuing Care. This should take into account the range and levels of need recorded in the Decision Support Tool. Any disagreement on levels used or areas where needs have been counted against more than one domain should be highlighted here. The DST is not a stand-alone tool and is designed to ensure that relevant needs are assessed, captured and described in a consistent way. Reaching a recommendation on whether the child or young person meets eligibility for continuing care should include consideration of:**

**Risk** assessments should be undertaken during the assessment phase and should be used for appraising options for delivery of care.

**Intensity:** This relates to both the extent (‘quantity’) and severity (degree) of the needs and the support required to meet them, including the need for sustained/ongoing care (‘continuity’).

**Complexity:** This is concerned with how the needs present and interact to increase the skill needed to monitor the symptoms, treat the condition(s) and/or manage the care. This can arise with a single condition or can also include the presence of multiple conditions or the interactions between two or more conditions.

Each of these characteristics may, in combination or alone, demonstrate continuing care needs.

Also please indicate whether needs are expected to change (in terms of deterioration or improvement) before the case is next reviewed. If so, please state why and what needs you think will be different and therefore whether you are recommending that eligibility should be agreed now or that an early review date should be set

**The preferences of the child or young person and their family**

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

This area corresponds to section A in the Education, Health and Care plan, which captures the views, interests and aspirations of the child or young person, and their parents.

**Holistic assessment of the child or young person**

The nominated children and young person’s health assessor undertakes a health assessment, collating existing assessments, including for social care. Where social and educational assessments have not been undertaken, the assessor should liaise with the appropriate professionals.

The health needs of other family members and the proposed environment of care should also be considered. The Decision Support Tool for children and young people provides some prompts to help shape this part of the assessment.

**Reports and risk assessments from the professionals in the child’s multidisciplinary team**

The nominated children and young people’s health assessor is responsible for collating the evidence from professionals who are involved in the care of the child or young person (across health, social and education), particularly risks assessments and reports. There may also be a need to commission healthcare risk assessments that have not already been undertaken. As in all elements of the assessment, the health assessor may need to get expert advice on this, and is not expected to act as a specialist in all areas of the child or young person’s care.

This again is similar to the co-ordinated assessment of the EHC process. In many cases, the assessor will be able to receive a written report and / or risk assessment from the relevant professionals based on their notes (and often, a copy of the relevant section of the notes will suffice).

**Recommendation**

|  |
| --- |
| Recommendation on eligibility for Continuing Care detailing the conclusions on the issues outlined on the previous page: |
| **Prompts for writing the recommendation:** **Risk*** Risk assessments undertaken during the assessment phase can be used for appraising options for delivery of care.
* Apply risk scores and ratings

**Intensity:** * How severe is the need?
* How problematic is to alleviate the needs and/or symptoms?
* How often is a nursing/therapeutic intervention required and how long does it take?
* How much care is needed?
* Is the care routine or are other interventions required in between planned care?
* How many carers are required
* Does the care relate to needs over several domains?
* How much time does the Nurse, Doctor or Therapist spend with the individual

**Complexity:** * Is the child/young person presenting with a challenge to manage by care staff?
* How difficult is it to manage the child/young person’s care needs?
* Are the needs interrelated between the care domains?
* Does the impact of one care need with another make it more difficult to meet the individual’s care needs?
* How much knowledge is required to address the needs?
* How much skill is required to address the needs?
* Indicate whether needs are expected to change (in terms of deterioration or improvement). If so, please state why and what needs you think will be different and therefore whether you are recommending that eligibility should be agreed now or that an early review date should be set

**The preferences of the child or young person and their family:** * the views of all family members including siblings

**Holistic assessment of the child or young person:** * other agencies assessments of the child/young person.
* The health needs of other family members and the proposed environment of care should also be considered.
 |
| **Eligibility for Continuing Care** | **Yes** | **No** |

**Signatures of those present when DST completed:**

|  |  |  |  |
| --- | --- | --- | --- |
| **Name****(please print)** | **Signature** | **Professional qualification (if applicable)** | **Date** |
|  |  |  |  |

## About you - Equality Monitoring

Please provide us with some information about yourself. This will help us to understand whether everyone is receiving fair and equal access to NHS continuing Care. All the information you provide will be kept completely confidential. No identifiable information about you will be passed on to any other bodies, members of the public or press.

1. What is your sex? Tick one box only.

|  |  |
| --- | --- |
| Male |  |
| Female |  |

1. Which age group applies to you?

|  |  |
| --- | --- |
| 0 - 15 |  |
| 16 - 24 |  |

1. What is your ethnic group?
2. White

|  |  |
| --- | --- |
| British |  |
| Irish |  |

Any other White background, write below

|  |
| --- |
|  |

1. Mixed

|  |  |
| --- | --- |
| White and Black Caribbean |  |
| White and Black African |  |
| White and Asian |  |

Any other Mixed background, write below

|  |
| --- |
|  |

1. Asian, or Asian British

|  |  |
| --- | --- |
| Indian |  |
| Bangladeshi |  |
| Pakistani |  |

Any other Asian background, write below

|  |
| --- |
|  |

1. Black, or Black British

|  |  |
| --- | --- |
| Caribbean |  |
| African |  |

Any other Black background, write below

|  |
| --- |
|  |

1. Chinese, or other ethnic group

|  |  |
| --- | --- |
| Chinese |  |

Any other, write below

|  |
| --- |
|  |

1. Do you have any religious or cultural beliefs – please state

Yes

No