**Children and young people’s continuing care pre-assessment checklist** \*If scoring HIGH or above, please include relevant documentation to support your referral

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| **Child or young person’s details** | | | | |
| **Name** |  | | | |
| **Date of birth** |  | **NHS Number** | |  |
| **Address** |  | | | |
| **Gender** (delete as appropriate) | **MALE** | **FEMALE** | | |
| **First language (if not English)** |  | **Translator needed** | | |
| **Other communication**  **support needed** | | |
| **Mother / Caregiver name** |  | **Father / Caregiver 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** |  | |

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| **Address of GP practice** |  |
| **Name of GP** (if child or young person has a named doctor) |  |
| **Clinical commissioning group** (where known): |  |
| **Local authority** (where known) |  |

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| **Medical history** |
| Provide a brief summary below of the child or young person’s primary health needs, with details of any diagnoses and provision. |
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| **Social care** |
| Provide a brief summary below of the child or young person’s social care needs with details of any arrangements in place. |
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| **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?** |  |
| **Does the child or young person have special educational needs?** |  |

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| **Consent** | | | | |
| **Please obtain verbal consent**  This referral cannot be accepted without consent | **Child / Young Person** | | **Parent / Carer** | |
| **They are 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 |
| **They have been involved / contributed to the completion of this referral/checklist?**  **(delete as appropriate).** | Yes | No | Yes | No |

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| **Details of pre-assessment** | | |
| **Date of pre-assessment (completion)** | |  |
| **Name of assessor**  (use the box below for details of other contributors.) | |  |
| **Employer** | |  |
| **Contact no.** | |  |
| **E-mail** | |  |
| **How was the referral for continuing care made?** | |  |
| If other individuals / organisations support the child or young person, and have contributed to the pre-assessment, please give details below. Supportive evidence can be attached. | | |
| **1.** | **Name** |  |
| **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** |  |
| **2.** | **Name** |  |
| **Organisation** |  |
| **Role in relation to the child or young person** |  |
| **Nature of contribution** |  |
| **Contact no.** |  |
| **E-mail** |  |
| **3.** | **Name** |  |
| **Organisation** |  |
| **Role in relation to the child or young person** |  |
| **Nature of contribution** |  |
| **Contact no.** |  |
| **E-mail** |  |
| **4.** | **Name** |  |
| **Organisation** |  |
| **Role in relation to the child or young person** |  |
| **Nature of contribution** |  |
| **Contact no.** |  |
| **E-mail** |  |

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| **Existing assessments** | | | |
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| **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 | \*If scoring HIGH or above, please include relevant documentation to support your referral |
| 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 |  |

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| **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 | \*If scoring HIGH or above, please include relevant documentation to support your referral |
| The majority of fluids and nutritional requirements are routinely taken by intravenous means. | Severe |  |

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| **MOBILITY** |  |  |
| **Description** | **Level of need** | **Comment** |
| 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 | \*If scoring HIGH or above, please include relevant documentation to support your referral |
| 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 | \*If scoring SEVERE please include relevant documentation to support your referral |

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| **CONTINENCE OR ELIMINATION** |  |  |
| **Description** | **Level of need** | **Comment** |
| 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 | \*If scoring HIGH or above, please include relevant documentation to support your referral |
| Requires dialysis in the home to sustain life. | Severe | \*If scoring SEVERE please include relevant documentation to support your referral |

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| **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** | **Comment** |
| 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 | \*If scoring HIGH or above, please include relevant documentation to support your referral |
| Life-threatening skin conditions or burns requiring complex, painful dressing routines over a prolonged period. | Severe | \*If scoring SEVERE please include relevant documentation to support your referral |

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| **COMMUNICATION** |  |  |
| **Description** | **Level of need** | **Comment** |
| 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 | \*If scoring HIGH or above, please include relevant documentation to support your referral |

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| **DRUG THERAPIES AND MEDICATION** |  |  |
| **Description** | **Level of need** | **Comment** |
| 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 | \*If scoring HIGH or above, please include relevant documentation to support your referral |
| 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 | \*If scoring SEVERE please include relevant documentation to support your referral |
| 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 |  |

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| **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** | **Comment** |
| Psychological or emotional needs are apparent but typical of age and similar to those of peer group. | No additional needs |  |
| Periods of emotional distress (anxiety, mildly lowered mood) not dissimilar to those typical of age and peer group, which subside and are self-regulated by the child/young person, with prompts/ reassurance from peers, family members, carers and/or staff within the workforce. | Low |  |
| Requires prompts or significant support to remain within existing infrastructure; periods of variable attendance in school/college; noticeably fluctuating levels of concentration. Self-care is notably lacking (and falls outside of cultural/peer group norms and trends), which may demand prolonged intervention from additional key staff; self-harm, but not generally high risk; | Moderate |  |
| Evidence of low moods, depression, anxiety or periods of distress; reduced social functioning and increasingly solitary, with a marked withdrawal from social situations; limited response to prompts to remain within existing infrastructure (marked deterioration in attendance/attainment / deterioration in self-care outside of cultural/peer group norms and trends). | High | \*If scoring HIGH or above, please include relevant documentation to support your referral |

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| **SEIZURES** |  |  |
| **Description** | **Level of need** | **Comment** |
| **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 | \*If scoring HIGH or above, please include relevant documentation to support your referral |
| 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 | \*If scoring SEVERE please include relevant documentation to support your referral |

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| **CHALLENGING BEHAVIOUR** |  |  |
| **Description** | **Level of need** | **Comment** |
| 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 | \*If scoring HIGH or above, please include relevant documentation to support your referral |
| 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 | \*If scoring SEVERE please include relevant documentation to support your referral |
| 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 |  |

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| **TOTAL SCORES** | |
| No Additional Needs |  |
| Low |  |
| Moderate |  |
| High |  |
| Severe |  |
| Priority |  |

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| **Child meets Continuing Care Criterion for assessment** | | |
|  | **Yes** | **No** |
| Three ‘High’ ratings |  |  |
| One ‘Severe’ rating |  |  |
| One ‘Priority’ rating |  |  |