

## Breathing - assessors should indicate the level of need

Description	Level of need
Breathing typical for age and development.	No additional needs
Routine use of inhalers, nebulisers, etc.; <b>or</b> 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; <b>or</b> intermittent or continuous low-level oxygen therapy is needed to prevent secondary health issues; <b>or</b> supportive but not dependent non-invasive ventilation which may include oxygen therapy which does not cause life-threatening difficulties if disconnected; <b>or</b> child or young person has profoundly reduced mobility or other conditions which lead to increased susceptibility to chest infection (Gastroesophageal Reflux Disease and Dysphagia); <b>or</b> requires daily physiotherapy to maintain optimal respiratory function; <b>or</b> requires oral suction (at least weekly) due to the risk of aspiration and breathing difficulties; <b>or</b> 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; <b>or</b> 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; <b>or</b> requires continuous high level oxygen dependency, determined by clinical need; <b>or</b> has a need for daily oral pharyngeal and/or nasopharyngeal suction with a management plan undertaken by a specialist practitioner; <b>or</b> 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); <b>or</b> severe, life-threatening breathing difficulties, which require essential oral pharyngeal and/or nasopharyngeal suction, day or night; <b>or</b> a tracheostomy tube that requires frequent essential interventions (additional to routine care) by a fully trained carer, to maintain an airway; <b>or</b> 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; <b>or</b> has no respiratory drive when asleep or unconscious and requires ventilation, disconnection of which could be fatal; <b>or</b> a highly unstable tracheostomy, frequent occlusions and difficult to change tubes.	Priority

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

Description	Level of need
Able to take adequate food and drink by mouth, to meet all nutritional requirements, typical of age.	No additional needs
<p>Some assistance required above what is typical for their age;</p> <p><b>or</b></p> <p>needs supervision, prompting and encouragement with food and drinks above the typical requirement for their age;</p> <p><b>or</b></p> <p>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;</p> <p><b>or</b></p> <p>needs feeding when this is not typical for age, but is not time consuming or not unsafe if general guidance is adhered to.</p>	Low
<p>Needs feeding to ensure safe and adequate intake of food; feeding (including liquidised feed) is lengthy; specialised feeding plan developed by speech and language therapist;</p> <p><b>or</b></p> <p>unable to take sufficient food and drink by mouth, with most nutritional requirements taken by artificial means, for example, via a non-problematic tube feeding device, including nasogastric tubes.</p>	Moderate
<p>Faltering growth, despite following specialised feeding plan by a speech and language therapist and/or dietician to manage nutritional status,.</p> <p><b>or</b></p> <p>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);</p> <p><b>or</b></p> <p>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;</p> <p><b>or</b></p> <p>problems relating to a feeding device (e.g. nasogastric tube) which require a risk-assessment and management plan undertaken by a speech and language therapist and multidisciplinary team and requiring regular review and reassessment. Despite the plan, there remains a risk of choking and/or aspiration.</p>	High
The majority of fluids and nutritional requirements are routinely taken by intravenous means.	Severe

## Mobility - assessors should indicate the level of need

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. <b>or</b> moves with difficulty (e.g. unsteady, ataxic); irregular gait.	Low
Difficulties in standing or moving even with aids, although some mobility with assistance. <b>or</b> 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; <b>or</b> 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; <b>or</b> at a high risk of fracture due to poor bone density, requiring a structured management plan to minimise risk, appropriate to stage of development; <b>or</b> involuntary spasms placing themselves and carers at risk; <b>or</b> 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; <b>or</b> positioning is critical to physiological functioning or life.	Severe

### Continence or elimination - assessors should indicate the level of need

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

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

Description	Level of need
No evidence of pressure damage or a condition affecting the skin.	No additional needs
Evidence of pressure damage or a minor wound requiring treatment; <b>or</b> skin condition that requires clinical reassessment less than weekly; <b>or</b> well established stoma which requires routine care; <b>or</b> has a tissue viability plan which requires regular review.	Low
Open wound(s), which is (are) responding to treatment; <b>or</b> active skin condition requiring a minimum of weekly reassessment and which is responding to treatment; <b>or</b> high risk of skin breakdown that requires preventative intervention from a skilled carer several times a day, without which skin integrity would break down; <b>or</b> 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; <b>or</b> active long-term skin condition, which requires a minimum of daily monitoring or reassessment; <b>or</b> 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 - assessors should indicate the level of need

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

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

Description	Level of need
Medicine administered by parent, carer, or self, as appropriate for age.	No additional needs
Requires a suitably trained family member, formal carer, teaching assistant, nurse or appropriately trained other to administer medicine due to <ul style="list-style-type: none"> <li>• age</li> <li>• non-compliance</li> <li>• type of medicine;</li> <li>• route of medicine; and/or</li> <li>• site of medication administration</li> </ul>	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; <b>or</b> monitoring because of potential fluctuation of the medical condition that can be non-problematic to manage; <b>or</b> 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; <b>or</b> sleep deprivation caused by severe distress due to pain requiring medication management – occurring four times a night (and four times a week). <b>or</b> 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; <b>or</b> extensive sleep deprivation caused by severe intractable pain requiring essential pain medication management – occurring every one to two hours <b>or</b> 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) – assessors should indicate the level of need**

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

Description	Level of need
Psychological or emotional needs are apparent but typical of age and similar to those of peer group.	No additional needs
Periods of emotional distress (anxiety, mildly lowered mood) not dissimilar to those typical of age and peer group, which subside and are self-regulated by the child/young person, with prompts/ reassurance from peers, family members, carers and/or staff within the workforce.	Low
Requires prompts or significant support to remain within existing infrastructure; periods of variable attendance in school/college; noticeably fluctuating levels of concentration. Self-care is notably lacking (and falls outside of cultural/peer group norms and trends), which may demand prolonged intervention from additional key staff; self-harm, but not generally high risk; <b>or</b> 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; <b>or</b> 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 – 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; <b>or</b> 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; <b>or</b> up to three tonic-clonic seizures every night requiring regular supervision.	Moderate
Tonic-clonic seizures requiring rescue medication on a weekly basis; <b>or</b> 4 or more tonic-clonic seizures at night.	High
Severe uncontrolled seizures, occurring at least daily. Seizures often do not respond to rescue medication and the child or young person needs hospital treatment on a regular basis. This results in a high probability of risk to his/her self.	Severe

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

Description	Level of need
No incidents of behaviour which challenge parents/carers/staff.	No additional needs
Some incidents of behaviour which challenge parents/carers/staff but which do not exceed expected behaviours for age or stage of development and which can be managed within mainstream services (e.g. early years support, health visiting, school).	Low
Occasional challenging behaviours which are more frequent, more intense or more unusual than those expected for age or stage of development, which are having a negative impact on the child and their family / everyday life.	Moderate
Regular challenging behaviours such as aggression (e.g. hitting, kicking, biting, hair-pulling), destruction (e.g. ripping clothes, breaking windows, throwing objects), self-injury (e.g. head banging, self-biting, skin picking), or other behaviours (e.g. running away, eating inedible objects), despite specialist health intervention and which have a negative impact on 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