



Vulnerability Factors considered for acceptance of Children with Cerebral Palsy or other *static* neurological conditions to Children's Hospice services

Around 18% of children with cerebral palsy die in childhood. Acceptance criteria for children's hospices usually require the child to be likely to be life limited by the age of 25 years. This means that it is likely that only around a quarter of all children with cerebral palsy will be accepted. Selecting the children most in need of specialist palliative care poses a challenge, in view of the unpredictability and uncertainty in the natural history of the condition. Most children succumb to respiratory illness, severe epilepsy or gastrointestinal problems. The enclosed chart is informed by evidence-based vulnerability factors, according to survival studies in acquired static brain injury. It can be used as a guide when considering referring children. Please feel free to contact your local children's Hospice to discuss cases that fall into a 'grey area', as the referrals team will usually be happy to discuss these. The references below form the basis for the chart, which divides areas of physiological vulnerability into 'green' (lower risk), 'yellow' (medium risk), 'orange' (higher risk), and 'red' (most vulnerable).

References

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3. Crichton JU, Mackinnon M & White CP (1995) The life-expectancy of persons with cerebral palsy. Dev Med & Child Neurol 37(7): 567-576
4. Hutton JL, Colver AF & Mackie PC (2000) Effect of severity of disability on survival in north east England cerebral palsy cohort Arch Dis Child 83(6): 468-474
5. Hutton JL & Pharoah POD (2002) Effects of cognitive, motor and sensory disabilities on survival in cerebral palsy, Arch Dis Child 86:84-89
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7. Siden H, Tucker T, et al (2009) Paediatric enteral feeding intolerance: a new prognosticator for children with life limiting illness? J Palliative Care 25(3): 213-217
8. Fairhurst C (2012) Cerebral Palsy: the whys and hows Arch Dis Child Educ Pract Ed 97: 122-131



The following is a guide to the sort of vulnerability factors that make a child with **cerebral palsy** (or other **static** neurological condition) likely to meet criteria for Children's Hospice services and to benefit most from specialist palliative care. Children likely to be accepted would have dark orange / red features in more than one category, and the answer to the last question would be 'yes'.

Respiratory Factors

- Frequent or increasing number of lower respiratory infections
- PICU admission for lower respiratory tract infection
- Requirement for long term oxygen therapy or non-invasive ventilation at home
- Tracheostomy and / or 24 hour ventilation

Feeding Factors

- Gastrostomy
- Jejunostomy
- Severe uncontrolled reflux despite maximum treatment
- Losing weight due to feeding difficulties
- Pain / distress associated with feeding, necessitating progressive feed reduction

Seizure related factors

- Epileptic activity needing medication
- Poor seizure control despite numerous drugs
- Frequent use of rescue medication (daily basis)
- Episodes of status epilepticus requiring intensive treatment (IV infusions / PICU)

Locomotor Factors

- Spastic quadriplegia / total body involvement
- Poor head control/ fixed spinal curvature
- Dependent on a wheelchair driven by a carer
- Difficulty with maintaining sitting position (Gross Motor Function Classification System Level V)

Other Neurological vulnerability to consider

- Other evidence of severe bulbar involvement (worsening swallow, cough, gag reflex)
- Baclofen pump (as a marker of severe hypertonia / very difficult spasms)
- Severe visual impairment (registered blind)
- VP shunt (particularly with frequent need of review)

In the light of the factors above, would you be surprised if the child was still alive at the age of 18 years?