HCCP Scoring Tool	Points applicable	Points scored
Respiratory - use highest score (max 4)		
Frequent or increasing lower respiratory infections	1	
PICU admission for lower respiratory infection	2	
Requirement for long term oxygen or non-invasive ventilation at home	3	
Tracheostomy and/or 24 hour ventilation	4	<u> </u>
Feeding - use highest score (Max 4)		
Gastrostomy/long term NG feeding (>6 months)	1	
Jejunostomy or severe uncontrolled reflux despite maximum treatment	2	
Losing weight or unable to administer essential medication due to feeding difficulties	3	
Pain/distress associated with feeding, causing progressive feed reduction or requirement for total parenteral nutrition	4	
Locomotor - use highest score (Max 4)		
Whole body movement disorder/quadriplegia/myopathy	1	
Fixed scoliosis/GMFCS Level V	2	
GMFCS Level V equivalent with dystonia/no voluntary movement	3	
Difficulty with maintaining comfort in seating e.g. inoperable progressive scoliosis, intractable dystonic pain, pressure sores etc.	4	
Seizures - use highest score (Max 4)		
Epilepsy requiring medication	1	
Poor seizure control despite at least three regular medications	2	
Frequent use of rescue medication (most days)	3	1
Episodes of status epilepticus requiring intensive treatment (IV infusions/PICU) or for which these are seen as futile	4	
Other medical interventions - use highest score (Max 4)		
Stoma/Insulin or clotting factor dependent	1	
Indwelling central access/long term urinary catheterisation/VP shunt/awaiting cardiac or neurosurgery	2	
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Organ transplant/Dialysis/Intra-ventricular medication	J	_