

Long Term Ventilation in Children

Notes to assessment process for LTV Decision Making

June 2020

Notes to Assessment Process for LTV Decision Making

- The potential need for LTV is most likely to be identified by staff in NICU, PICU, Neurology and Respiratory Services although there may be other services in which from time to time consideration of the need for LTV in a child arises i.e. where an acute spinal injury has occurred
- It is important that a MDT Pre Assessment meeting occur as soon as LTV may be a possibility, triggers for requesting a MDT Pre Assessment may include children with the following conditions: Severe transverse myelitis, neuromuscular disorders (myopathy), NF1, Duchene's muscular dystrophy, respiratory failure due to premature birth or as new born, acquired CNS disorder, congenital heart disease. Or when a request is made to the ENT Service for insertion of a tracheostomy.
- It is particularly important to have a discussion early in progressively deteriorating patients; the trigger for MDT Pre Assessment may be the increasing requirement for non-invasive ventilation, depending on the natural history of the child's diagnosis.
- A request for multidisciplinary team (MDT) Pre Assessment meeting can be initiated by anyone involved in the child's care via a request to the Clinical Nurse Specialist (CNS) for LTV (yet to be appointed) or the CNS for PICU Long Term Patient Coordination
- Once the process is triggered by a request for a Pre Assessment MDT meeting it is important that the full process is followed and that this is clear to all
- Members of the MDT will be determined on a case by case basis but would always include the Primary Physician, a PICU Physician and Respiratory Physician. Other members of the MTD may include a NICU Physician, Consult Liaison Physician, representation from other medical specialities involved, Clinical Nurse Specialist (CNS) for LTV (yet to be appointed) or the CNS for PICU Long Term Patient Coordination, a member of the child's care team who has a close relationship with the child and family and is actively involved in the child's care.
- Ensure all relevant information is gathered prior to the MDT Pre Assessment meeting.
- The purpose of the MDT Pre Assessment meeting is to determine if there is a clear medical need for long term ventilation that is in keeping with international best practice and NZ legal precedents.
- It may be necessary to meet more than once to reach a consensus or to widen the MDT consultation and possibly to engage with the Clinical Ethics Advisory Group to achieve an agreed way forward.
- If the decision of the MDT Pre Assessment process is to offer a formal LTV Assessment to the family the focus will be on following the guiding principles for decision making ensuring the child is the central focus of decision making, aimed at optimising the child's wellbeing and including comprehensive consideration of the child's whānau/family.
- If the outcome of the formal assessment is agreement to proceed with LTV the care pathway for LTV will be followed.

Diagram X: Assessment Process for LTV Decision Making

