Long Term Ventilation in Children
Guiding Principles for Decision Making
For consideration by the Clinical Ethics Advisory Group
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Contributors: John Beca (Director Child Health – Surgical, Cardiac and ICU), Emma Maddren (GM Child Health), Helen Evans (Clinical Director – Medical Specialties Service), Helen Waldron (Nurse Unit Manager – Medical Services), Louise Webster (Clinical Director Consult Liaison Services), David McNamara (Clinical Lead – Paediatric Respiratory Services), Malcolm Batten (Neonatologist), David O’Grady (Neurologist), Claire Campbell (Legal Counsel), Fiona Miles (Consultant Paediatric Intensivist), Mariam Buksh (Clinical Director – Newborn Services), Melinda Nolan (Clinical Director - Neuroservices), Helen Wihongi (Director Māori Health Research) Jacob Twiss (Paediatric Respiratory and Sleep Specialist), Liz Edwards (Paediatric Respiratory and Sleep Specialist), Nikki Mills (Paediatric ENT Specialist)

Introduction
Worldwide the number of children dependent upon the use of long term ventilation (LTV) to sustain life is increasing. New Zealand is experiencing a similar trend to that seen internationally. In the past five years Starship Child Health has assisted five families make the transition to home with their child dependent upon the use of LTV for significant periods of the day and in some cases totally dependent upon ventilator support.

The decision to proceed with LTV is complex, usually made at a time when family and health professionals are faced with life-limiting or life-threatening conditions and when there is often also uncertainty and differing views about goals of care and what is reasonable and appropriate treatment for a child.

Parallel development of ethical frameworks for decision making in long term ventilation in children is evolving internationally however there is no consensus as to best practice. The multidisciplinary paediatric team at Starship Child Health are seeking to determine guiding principles for decision making about long term ventilation that reflect the range of cultures, values and clinical practice of New Zealand life.

The goal is for each child to live life to their maximum potential, in the best possible environment.

Definition of LTV
A child is dependent on ventilatory support to maintain life either in sleep alone or both awake and asleep. Risk of death or significant harm exists where the loss of ventilator support or the artificial airway for even brief periods (minutes) occurs during the dependent time.

Legal framework
For children less than 16 years of age a guardian has the legal authority to consent to medical treatment of the child.

Where there are significant differences in perspective between the clinical team and the legal guardians and agreement cannot be reached, application can be made to the High Court or the Family Court to place a child under the Guardianship of the Court under the Care of Children Act. If the application is successful, the Court will appoint an agent or agents (usually one or two of the treating doctors) to consent to medical treatment or the withdrawal of medical treatment. In such cases the paramount consideration will be the welfare of the child.

In Auckland Healthcare Services Ltd v L (1998) 17 FRNZ 376 (HC), The High Court considered the following factors were necessary to consider in applying the best interests test:

- The relevant rights (the right not to be deprived of life);
- The therapeutic or medical benefit;
- The chance of recovery;
- The parents’ views;
- The impact of the treatment on the child.
Guiding principles for decision-making when a child requires long-term ventilation to sustain life*

1. Is it in the child’s best interests to provide long-term ventilation?

1.1. The child should be the central focus of all decision making, aimed at optimising the child’s wellbeing across all domains (physical, emotional, intellectual, social). Decision making should include comprehensive consideration of the child’s whānau /family and wider support networks.

1.2. There should be a clear medical need for ventilation with benefits of on-going intensive medical therapy outweighing the burdens for a particular child in their whānau/family context. Medical indications and practices for LTV in NZ should be in keeping with international best practice and NZ legal precedents.

1.3. There should be consensus between the clinical team and the legal guardian that the child is able to be safely cared for at home or in the community and that the advantages of long term ventilation outweigh the disadvantages for the child in accordance with their anticipated clinical trajectory.

1.4. The goal of LTV for each child should be determined. It is important to determine whether ventilation is intended to bridge a period of time over which recovery is anticipated or whether it is a destination treatment with the expectation LTV will be lifelong.

1.5. Where a child is competent (or likely to develop competence) and be able to communicate their wishes, these should be incorporated into decision making. Legal competence to consent is not usually legally upheld until the child reaches 16 years, although children’s wishes are taken into account at much younger ages in the courts.

2. Decision making should be informed, inclusive, empathetic and without judgement

2.1. Cultural and spiritual values and beliefs of the child and their caregivers should be considered in all decision making. However the child’s best interests should be paramount and take precedence over the interests of parents or guardians in nearly all situations (paramountcy principle).

2.2. There should be multidisciplinary assessments and discussions about the likely clinical course for a specific child, instigated as early as possible following identification of a potential need for long term ventilation. Where further information is required, this should be obtained before decisions are finalised. Temporising life prolonging therapy such as tracheostomy insertion may be required during this period and should be clearly communicated to the caregivers.

2.3. The primary caregiver should be considered to be the default carer for the child on LTV. The caregiver should consent to undertake this role after due consideration of all relevant information. (Where there will be a substitute carer, there should be agreement by all parties that the substitute is socially and legally appropriate to take this role). Full assessment of the primary caregiver’s psychosocial capacity and logistic capability should include evaluation of their understanding of the burden of care involved and support systems available to them.
2.4. Caregivers and stakeholders should be engaged early in the decision making process, with all parties receiving accurate, consistent, up to date information comprising indications for LTV, potential complications, psychosocial issues, and long term implications. There should be open discussion about management of life threatening events and potential changes in the child’s clinical condition which may suggest the need to reconsider the appropriateness of on-going ventilatory support, (particularly where a condition is likely to progress or change).

2.5. Palliative care should be considered integral to a long term ventilation management plan and incorporated from the outset.

2.6. Likely clinical trajectory should be discussed by all relevant medical practitioners and stakeholders. The child’s functional status and likely clinical progression should be given greater weight than the diagnosis\(^1\). Where the outcome is uncertain, a review date and plan should be agreed for reassessment with provision for facilitating earlier review if necessary. Specific decisions should be based on current knowledge and available treatments rather than possible future developments.

2.7. Impact and burden of assessed level of care required should be openly discussed by all involved to determine whether benefit to the child outweighs the burden to all involved\(^2\) and the impact and potential harm to the child including impact on development. Expectations of carers and support services should be clearly outlined. Carers should be given full information about their roles and responsibilities relating to a child with LTV and be motivated and consent to undertake all necessary training.

2.8. Decisions should be based on a shared decision making model with all caregivers and stakeholders involved having opportunity to express their views. Goals of care should be defined and agreed to before specific management plans are outlined.

2.9. Formal records of communications should be kept and distributed to all stakeholders.

2.10. Where there is disagreement about goals of care or expectations differ between medical teams and caregivers, between medical teams, or between any other parties, a formal process should be instigated early to prevent miscommunication or conflict developing. (See guidelines for dispute resolution below).

2.11. While decision making for an individual child should be based on factors specific to that child, there should be equity and consistency in decision making. Resource implications should be considered to ensure equitable distribution of resources.

2.12. Ventilation (in any form) introduced as a temporary life saving measure should not be considered as a justification for long term ventilation. The decision to withdraw treatment such as ventilation should not be considered ethically distinct from the decision not to provide that treatment.

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\(^1\) Ray, S et al. Towards developing an ethical framework for decision making in LTV for children. 2018

\(^2\) Dybwik. Ethical challenges in home mechanical ventilation. 2015
3. A quality process must support decision making to ensure a quality outcome for the child

3.1. A primary facilitator or facilitating team should be identified with clear lines of responsibility for oversight of decision making and sharing of information, as soon as life support long term ventilation is considered.

3.2. All stakeholders and caregivers should be identified early and forums established for open and regular communication, recognising the process requires multiple conversations.

3.3. Goals of care should be agreed based on anticipated trajectory and whānau/family’s wishes.

3.4. Assessment of needs to achieve goals of care should be undertaken. This should include a multidisciplinary assessment of whether these goals can be realistically achieved within the child’s social environment.

3.5. Decision-making should be regarded as an on-going evolving process. A review process should outline specific points at which the clinical condition of the patient is reassessed to confirm whether LTV is still appropriate including once a child is at home and if the child gains the ability to consent to or decline on-going ventilation. In order to provide confidence and certainty to the family all members of the multidisciplinary team should express their collaborative support for decisions as they are made and adhere to the review plan agreed.

Dispute resolution process:

The following stages collectively form one possible dispute resolution process. Not all stages may be necessary or appropriate, nor is the order detailed below prescriptive. At each stage new insights or information should be shared with all parties with the aim to achieve resolution.

High priority should be given at all stages to ensure all involved have access to appropriate counselling and support (patient, whānau, carers, nursing medical and allied staff).

1. Primary conversation with carers, lead medical team and support people.
2. Provide cultural and/or spiritual support
3. Appoint a primary facilitator (may be separate from primary medical consultant)
4. Multiple conversations involving all relevant interested parties
5. Involve cultural leaders and other relevant support parties (if not already engaged) to attempt to align goals of care and values and ascertain common ground.
6. Offer formal independent advocate for the patient / family
7. Formal mediation process / Hohou te rongo process
8. Obtain further medical opinions from independent experts
9. Consult with Clinical Ethics Advisory Committee
10. Clarify legal position
11. Consider court proceedings