Introduction

The purpose of this document is to provide a care pathway for patients being considered for Long Term Ventilation (LTV) via tracheostomy. The goal of this care pathway is to ensure timely clinical management, minimize system borne delays and facilitate safe transition home via Holland Bloorview Rehabilitation Hospital (HBRH). This care pathway aims to improve interprofessional communication, patient and family satisfaction and community partnerships.

Target Users

- Critical care: Advanced Practice Nurse/Nurse Practitioner, Dietitian, Physiotherapy, Occupational Therapy, Speech Language Pathologist, Social Worker, Staff Physician/Core Fellow, and Transitional Care Coordinator.
- ENT consult team
- Long-Term Ventilation team: Nurse Practitioner, Respiratory Therapist
- Respiratory Medicine consult team: Staff Physician, Fellow
- Connected Care Team: Registered Nurses, Respiratory Therapists

Target Patient Population

- Inclusion criteria: patients being considered for invasive ventilation via tracheostomy
- Exclusion criteria: patients who are not being considered for invasive ventilation

Acronyms

- ADP: Assistive Devices Program
- APN: Advanced Practice Nurse
- ARMS: Ambulatory Referral Management System
- ENT: Ear Nose and Throat
- HBRH: Holland Bloorview Rehabilitation Hospital
- HCCSS: Home and Community Care Support Services
- LTV: Long Term Ventilation
- Multi-D: multi-disciplinary
- NP: Nurse Practitioner
- OT: Occupational Therapy
- PACT: Paediatric Advanced Care Team
- PT: Physiotherapy
- RT: Respiratory Therapist
- SLP: Speech Language Pathologist
- SW: Social Worker
- TCC: Transitional Care Coordinator
- Trach: Tracheostomy
- Vent: Ventilator
- VEP: Ventilator Equipment Pool

©The Hospital for Sick Children (“SickKids”). All Rights Reserved. This document was developed solely for use at SickKids. SickKids accepts no responsibility for use of this material by any person or organization not associated with SickKids. A printed copy of this document may not reflect the current, electronic version on the SickKids Intranet. Use of this document in any setting must be subject to the professional judgment of the user. No part of the document should be used for publication without prior written consent of SickKids.
• VFS: Video fluoroscopy swallowing study

**Recommendations**

### LTV Pathway printable version

**About Kids Health Parent & Caregiver information**

• The care pathway highlights the process for referring to the LTV team and the patient journey that is divided into four key timeframes.
• Each timeframe includes defined tasks to be performed in sequence by team members involved in the patient’s care.
• Care goals are associated with each timeframe.
• The following is a high level overview of the LTV pathway.
• Please see the LTV pathway above for timelines and detailed roles of all key stakeholders.

**Pre-Tracheostomy: Panel 1**

• LTV pathway is activated by the Critical Care team upon the identification of a patient potentially requiring LTV via tracheostomy.
• Respiratory Medicine consultation, Otolaryngology-Head and Neck Surgery (ENT) as well as multidisciplinary referrals (PT/OT/SW/SLP/Dietician/TCC) are made by the Critical Care team.
• LTV team, consulted by Respiratory Medicine, meets with the child and family to discuss what life is like caring for a child receiving LTV at home.
• A multi-disciplinary meeting is held with the involved inter-professional clinicians and the family to support decision-making.
• This phase ends with the decision to move ahead with LTV or NOT to move ahead with LTV.

<table>
<thead>
<tr>
<th>Tasks</th>
<th>Care Goals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respiratory Medicine consult</td>
<td>Involvement of LTV team</td>
</tr>
<tr>
<td>LTV referral</td>
<td>Informed decision-making by family</td>
</tr>
<tr>
<td>LTV multi-D meeting</td>
<td>Placement of tracheostomy and initiation of ventilation (if applicable)</td>
</tr>
<tr>
<td>SW assessment</td>
<td>Education initiation (if applicable)</td>
</tr>
<tr>
<td>LTV information sharing with family</td>
<td></td>
</tr>
<tr>
<td>Refer to Connected Care Team for trach teaching (if applicable)</td>
<td></td>
</tr>
</tbody>
</table>

**Week 1-2 Post Tracheostomy: Panel 2**

• Discharge planning begins during this phase of the LTV pathway.
• The inter-professional team comes together to set a discharge date and to develop weekly action items, which are shared with the family. These include home and community care referrals, ADP applications and liaison with HBRH.
• An education schedule and teaching plan for tracheostomy care will be developed with the family by the Connected Care Team.
• ENT performs the first tracheostomy change.
• There is ongoing assessment of the child's medical stability and readiness for transfer to HBRH.

<table>
<thead>
<tr>
<th>Tasks</th>
<th>Care Goals</th>
</tr>
</thead>
<tbody>
<tr>
<td>• First trach change</td>
<td>• Stable airway and adequate ventilation</td>
</tr>
<tr>
<td>• G-tube insertion (if applicable)</td>
<td>• Optimization of nutrition</td>
</tr>
<tr>
<td>• Assessment of medical stability</td>
<td>• Medical stability</td>
</tr>
<tr>
<td>• Transfer to HBRH (if applicable)</td>
<td>• Transition to HBRH</td>
</tr>
<tr>
<td>• Completion of funding and equipment applications</td>
<td></td>
</tr>
<tr>
<td>• Ongoing education</td>
<td></td>
</tr>
</tbody>
</table>

**Week 3-4 Post Tracheostomy: Panel 3**

• This phase is characterized by ongoing discharge planning, family caregiver education and reassessment of medical stability.
• An education schedule and teaching plan for home ventilation will be developed with the family by the LTV team once tracheostomy education is complete.
• The inter-professional team follows up on ADP referrals, home and community care referrals and ordering of equipment and supplies.
• There is ongoing assessment of the child's medical stability and readiness for transfer to HBRH.

<table>
<thead>
<tr>
<th>Tasks</th>
<th>Care Goals</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Securing of home feeding supplies</td>
<td>• Home environment readiness</td>
</tr>
<tr>
<td>• Completion of home and community care referral (if applicable)</td>
<td>• Medical stability</td>
</tr>
<tr>
<td>• Assessment of medical stability</td>
<td>• Transition to HBRH</td>
</tr>
<tr>
<td>• Transfer to HBRH (if applicable)</td>
<td></td>
</tr>
<tr>
<td>• Completion of insurance letter and home O₂ application</td>
<td></td>
</tr>
<tr>
<td>• Ongoing education</td>
<td></td>
</tr>
</tbody>
</table>

**Week 5-8 Post Tracheostomy: Panel 4**

• The final phase is characterized by complete readiness for discharge home.
• Of note, transfer to HBRH may also occur during this phase.
• The completion of family caregiver training ends with a successful Care by Parent period.
• The child is medically stable on their current ventilator settings.
• Lastly, the community is ready for the child and family. This involves safe equipment and supply set-up in the home, clear follow up and emergency plans, as well as trained community nurses ready to care for the child in the home environment.

<table>
<thead>
<tr>
<th>Tasks</th>
<th>Care Goals</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Support for Care by Parent</td>
<td>• Caregiver competency and autonomy</td>
</tr>
<tr>
<td>• Establishment of community follow-up</td>
<td>• Transition to HBRH or home</td>
</tr>
<tr>
<td>• Establishment of home safety plan</td>
<td></td>
</tr>
<tr>
<td>• Assessment of medical stability</td>
<td></td>
</tr>
<tr>
<td>• Transfer to HBRH (if applicable)</td>
<td></td>
</tr>
</tbody>
</table>
Implementation Plan

- The LTV pathway steering committee met with key stakeholder representatives to determine milestones required for seamless transition of patients and families requiring LTV via tracheostomy.
- The care pathway has undergone multiple reviews by key stakeholder representatives and has been sent to their respective groups for review and feedback.
- Additionally, the care pathway was presented to the NICU and PICU inter-professional groups.
- The LTV team is committed to ongoing education and awareness building during fellow orientation for Respiratory Medicine. The LTV pathway steering committee is also committed to providing updates in practice to the Respiratory Medicine and Critical Care teams.

Evaluation Plan

- A mixed methods program evaluation study will be completed. Qualitative data will be collected via semi-structured interviews (pre=10, post =10) with family caregivers of children initiated on LTV via tracheostomy 2 years pre and post implementation of care pathway.
- Additionally, healthcare providers involved in the care of these patients will be asked to participate in focus groups.
- Quantitative data will be collected through healthcare records review including length of stay.

References


Guideline Group and Reviewers

Guideline Group Steering Committee:

1. Reshma Amin, MD, FRCPC, MSc, Staff Respirologist, Respiratory Medicine
2. Christine Clark, MHSc, RN, Senior Clinical Manager, Respiratory Medicine
3. Joanna Polyviou, NP-Pediatrics, Nurse Practitioner, Respiratory Medicine
4. Faiza Syed, RRT, Respiratory Therapist, Respiratory Medicine
5. Fatma Rajwani, MScPT, HBSc, Quality Analyst, Clinical Practice Guidelines Co-ordinator, Quality Management

Internal Reviewers:

1. Peter Cox, MD. Former Associate Chief and Division Head Pediatric Critical Care Unit, Critical Care Medicine (2018)

Acknowledgements for Participation in the Development of the LTV Pathway:

Kaitlin Ames, Karen Dryden-Palmer, Zelia Da Silva, Christina Sperling, Dr Evan Propst, Cindy Lott, Perihan Boyer, Jamil Lati, Dr Linh Ly, Judy Hawes, Michael Finelli, Ruta Niedra, Stephanie Dos Santos, Kathryn Schultz-Brown, Sally McMackin, Craig Campbell, Angela Lekavicus, Paul Gregoroff, Jessica Faust, Veronica Werhurst, Ashley Graham, Carly Mutch, Maggie Harkness, Cynthia Zhang, Krista Keilty, Stephanie Chu
Attachments:

About Kids Health Information for Parents Caregivers.pdf
Care by Parent Contract.docx
Care By Parent Guidelines.doc
Connect Care Tracheostomy Care Teaching Pathway.pdf
Criteria for Medical Stability.docx
Evaluation of Care by Parent.docx
final version july 2019.pdf
HFO Training Manual.pdf
KIDS VENT Tool.doc
Learning Activities Log with commitment statement.docx
LTV Information Sheet for Parents.docx
LTV Multi-D Meeting Template.pdf
LTV Caregiver Education Summary.doc
LTV Criteria.docx
LTV Inpatient Referral Form.doc
LTV Pathway Background Links to info and forms Feb 2.docx
Multi-D Discharge Planning Team.docx
Multi-D Team.docx
Readiness to Learn Criteria for LTV.docx
Sick Kids LHIN Blank Medical Referral.pdf
Transition Planning Multi-D Team.docx
Winnipeg Tracheostomy Decision Guide.pdf