



Title: PEDIATRIC / NEONATAL TRACHEOSTOMY: DECISION-MAKING AND PRE-TRACHEOSTOMY MANAGEMENT	Section: 80.210.1430	Approved Date: March 2009
Authorization Child Health Program Management Team	Revised Date: 24 May 2011	Page: 1 of 10

1.0 PURPOSE:

- 1.1 To describe the multidisciplinary team process for efficient and effective insertion of a non-emergent tracheostomy in pediatric and neonatal patients within the Child Health Program, Health Sciences Centre site.

2.0 BACKGROUND:

A tracheostomy is often regarded as the “solution” to a host of airway difficulties/chronic respiratory insufficiency and for many health care providers the surgical procedure is viewed as the final resolution. A tracheostomy is more than a procedure; for the child that requires chronic mechanical ventilation the tracheostomy is a life altering event which results in enormous challenges. These include not only the physical care and responsibility of the child but also significant psycho/social /family implications. This places the family under a great deal of stress, with the potential of divorce higher than the Canadian norm. The family may need to relocate based on the medical needs of the child; which is likely to impact the mental and physical health of parents and siblings. Most community resources are scarce and there is minimal ‘out-of-home’ respite available.

There are many reasons why a child may be considered for a tracheostomy but in most circumstances it is not the only choice. Recent medical and surgical advances have reduced the need for tracheostomy including advances in non-invasive ventilation techniques. A tracheostomy is not recommended to prolong inevitable death of the child. The decision to undergo this procedure is never to be taken casually. A multidisciplinary team is required to address the multitude of considerations about a non-emergent tracheostomy for a pediatric patient

3.0 MEDICAL INDICATIONS:

- 3.1 Indications for an emergency tracheostomy include, but are not limited to:
 - 3.1.1 Trauma.
 - 3.1.2 Congenital airway emergency.
 - 3.1.3 Medical airway emergency i.e. epiglottitis.
 - 3.1.4 Temporary tracheostomy for other medical indications (i.e. craniofacial surgical repair). These situations are likely to proceed directly to the Tracheostomy Team (see 7.0 in this document) for planning and education for tracheostomy.
- 3.2 Indications for non-emergent tracheostomy include, but are not limited to:
 - 3.2.1 Unstable airway.
 - 3.2.2 Prolonged mechanical ventilation.
 - 3.2.3 Progressive chronic respiratory failure.

4.0 CLINICAL SITUATION:

- 4.1 Clearly define the clinical situation to establish the need for a tracheostomy. Explore the following issues with all providers involved in the patient’s care:
 - 4.1.1 Specific knowledge of the pathophysiology of the disease process.
 - 4.1.2 Potential for clinical improvement or clinical stability.
 - 4.1.3 Potential long-term outcome.
 - 4.1.4 Outstanding test results or further diagnostic options.
- 4.2 When considering a non-emergent tracheostomy, consult the Tracheostomy Team through the Pediatric Respiriology Department. See section 7 for more details.

Title: Pediatric / Neonatal Tracheostomy: Decision-Making and Pre-Tracheostomy Management	Date R1 24 May 2011	Page 2 of 10
--	--------------------------------------	------------------------

- 4.3 Identify the core team in addition to Pediatric Respiriology:
 - 4.3.1 Care coordinator Options: Nurse Clinician, Clinical Nurse Specialist or other health care professional.
 - 4.3.2 Physician Options: PICU or NICU attending, the pediatrician or a specialist. If this role is to be shared between attending physicians develop a clear communication strategy.
 - 4.3.3 Respiratory Therapy Clinical Lead.
 - 4.3.4 Social Worker responsible for carrying out family and community assessment.

5.0 ALTERNATE OPTIONS:

- 5.1 The health care team, pediatrician, sub specialists and the family clarify the goal of care, the implications of the potential alternate options, and their impact on the patient, family and health care system.
 - 5.1.1 Possible alternative surgical or medical treatments may involve consults to subspecialists not yet involved. Consider all possible options carefully before tracheostomy.
 - 5.1.2 Continuation of current strategy with no escalation of treatments.
 - 5.1.3 Palliation and focus on symptom management with facilitation by the Pediatric Symptom Management and Palliative Care Service.
- 5.2 If there is evidence of an ethical dilemma or potential conflict, consult the “Ethics Consultation Service” if available. Contact them through the Health Sciences Centre paging operator.
- 5.3 The Pediatric Symptom Management and Palliative Care Service may be involved at any point during this exploration to contribute to the discussions.

6.0 FAMILY & COMMUNITY CONSIDERATIONS:

- 6.1 Explore the community and family resources with the following considerations:
 - 6.1.1 A child with a tracheostomy needs to have a trained caregiver with him/her at all time of the day and night.
 - 6.1.2 All caregivers are required to demonstrate skills and knowledge specific to the care for the child. This training is done in the hospital before discharge.
- 6.2 Before the tracheostomy procedure is done the hospital social worker facilitates assessment with the family. See Appendix C for an outline of the components of this assessment.
 - Provide a summary for the team which may incorporate the following:
 - Strengths and weaknesses (parent and support system);
 - Role difficulties;
 - Practical needs of patient and family;
 - Additional problems identified during assessment process;
 - Parents reaction/wishes regarding relocation if from outside Winnipeg
 - Parents identify and invite persons to meetings who are known as being supportive and willing to assist the family in decision making
- 6.3 Identify the family caregivers. Discuss with them their understanding of the impact of a tracheostomy and their required commitment.
- 6.4 Review available community resources found in Appendix B.
- 6.5 Involve Child and Family Services to explore potential medical foster home placement if the assessment indicates that the family’s home community is unable to provide the necessary supports and the family is unable to relocate.

7.0 TRACHEOSTOMY CONSULT TEAM:

- 7.1 The Child Health Tracheostomy Consult Team ensures all aspects of the child, family and community are adequately addressed, all alternate avenues explored and all members of the health care team are in agreement before proceeding to a tracheostomy.

Title: Pediatric / Neonatal Tracheostomy: Decision-Making and Pre-Tracheostomy Management	Date R1 24 May 2011	Page 3 of 10
--	--------------------------------------	------------------------

- 7.1.1 A member of the team completes an expedited review of the situation within 48 hours of the consult.
 - 7.1.2 If all points of consideration listed in Appendix D are favorable further review by the full team is not required.
 - 7.1.3 If any points are not favorable, or if it is felt that the larger team needs to review the case, the chair convenes a meeting within 5-7 days to make a recommendation. This meeting consists of at least 5 members as outlined in 8.3 and is chaired by an individual who is not directly involved in the patient's care.
 - 7.1.4 Results of both the expedited and full review are noted in the medical record by the team lead or designate.
- 7.2 The team composition is flexible for each situation to determine that individuals who are involved in the specific patient's care are not a part of the tracheostomy consult team for that situation. Intensivists represent the team for NICU patients and Neonatologists represent the team for PICU patients. Either one can represent the team for patients who are not in either area.
- 7.2.1 The tracheostomy team consists of:
 - Pediatric Respiriologist (present at all meetings)
 - General Surgeon or Otolaryngologist (present at all meetings)
 - Neonatologist / Intensivist
 - Nurse Clinician / Clinical Nurse Specialist
 - Medical Ethicist
 - Family Advisory Team Representative
 - Social Worker
 - Respiratory Therapist
 - Pediatric Symptom Management and Palliative Care Service member
 - If patient 14 years or older: Adult Respiriologist / Adult Long Term Ventilation Service Representative

8.0 CONFLICT RESOLUTION:

- 8.1 If a conflict arises between the family and caregivers or between various disciplines, the most important step towards resolution is communication. Gather as much information as possible and make every effort to be sure that each relevant team member and the family understands the information presented.
- 8.2 Face to face meetings are essential for making steps towards resolving conflicts and are planned with all necessary persons as determined by the Tracheostomy Team leader and the Medical Ethicist in as short a time as possible.
- 8.3 If the team is unable to resolve the conflict on their own, the following options are available:
 - 8.3.1 Direct the family to the Patient Representatives Office at 787-2704.
 - 8.3.2 Seek a neutral mediator from within the hospital.
 - 8.3.3 Enlist the assistance of the Child Health Department Head.

9.0 PLAN OF CARE:

- 9.1 Individualize the treatment and education plan depending on the situation. The following details are considered before plans for the tracheostomy procedure are finalized:
 - 9.1.1 Type of tracheostomy tube required: Equipment may need to be specially ordered and a set of three are to be on hand before the procedure date is booked.
 - 9.1.2 Ventilation needs: Respiratory Therapy prepares for potential increase or change in ventilation needs during the immediate and ongoing post-operative period.
 - 9.1.3 Monitoring needs: Potential safety risks are identified in order to anticipate the patient's post-operative and ongoing monitoring needs. These will determine the most appropriate location for the patient's ongoing care.
- 9.2 Determine the most appropriate post-operative care location and make sure that a bed is available in the patient care area before booking the surgery. Consider both immediate and ongoing care location.

Title: Pediatric / Neonatal Tracheostomy: Decision-Making and Pre-Tracheostomy Management	Date R1 24 May 2011	Page 4 of 10
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- 9.3 Ongoing caregivers: As care needs change conduct discussions regarding responsibility and agreements for directing care.

10.0 EDUCATION PROGRAM:

- 10.1 Arrange preliminary education with the family and members of the team as identified in 4.3. See the checklist in Appendix C to make sure the information is complete and the appropriate people are involved both in teaching and learning.
- 10.2 Educate the family not only about the tracheostomy but about their child, with the tracheostomy as part of the education.
- 10.3 Begin education as soon as the possibility of tracheostomy is raised. It is essential that the education is done by individuals who are likely to continue working with the family in the future. See Appendix E for the Pre-Tracheostomy Family Education Checklist.
- 10.4 Obtain educational materials which are part of the Children's Hospital Patient Education Program from the Family Information Library at CK204.

11.0 SURGICAL CONSIDERATIONS:

- 11.1 Consider the following points before a decision for the procedure is made:
- 11.1.1 Maximize medical management.
 - 11.1.2 The impact of co morbidities on the surgery.
 - 11.1.3 Potential future surgeries.
 - 11.1.4 Most appropriate timing of the procedure.
 - 11.1.5 Other procedures that may be done at the same time.
 - 11.1.6 Type of tracheostomy tube required and logistics for obtaining this equipment
- 11.2 Refer to the Guideline: Pediatric/Neonatal Tracheostomy: Post-Operative Management and Care Planning for post-operative care.

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Title: Pediatric / Neonatal Tracheostomy: Decision-Making and Pre-Tracheostomy Management	Date R1 24 May 2011	Page 5 of 10
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- 12.13 O'Brien, J.E. et.al (2007). Outcomes of post-acute hospital episodes for young children requiring airway support. *Developmental Neurorehabilitation*. 10(3):241-247.
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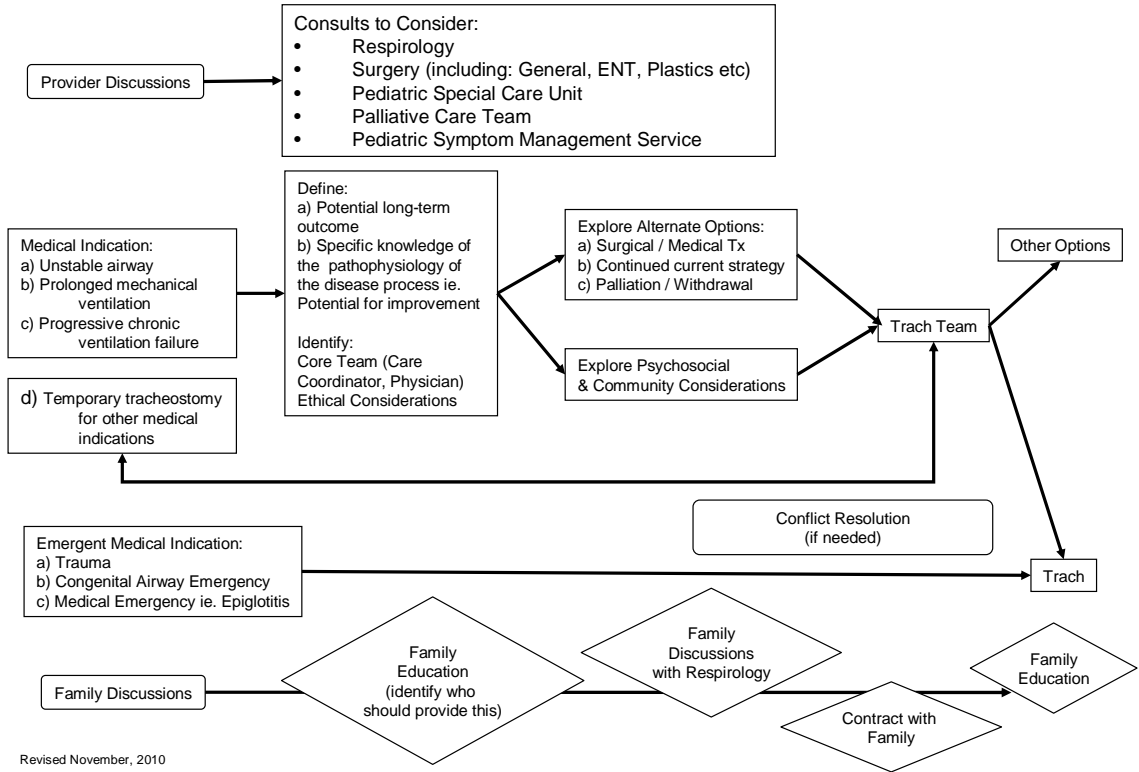
13.0 **RESOURCES:**

Members of the Child Health Tracheostomy Working Group (appointed by the Child Health Program Management Team) include:

- Respiriology
- Neonatology
- Pediatric Intensivist
- Pediatric General Surgeon
- Otolaryngologist
- Pediatrician
- Medical Ethicist
- Medical Director, Pediatric Symptom Management and Palliative Care Service
- Parent Advisor
- Pediatric Special Care Unit – Nurse Representative
- Respiriology Nurse Clinician
- Neonatal Clinical Nurse Specialist,
- Pediatric Symptom Management and Palliative Care Service - Clinical Nurse Specialist
- Pediatric Home Care Nurse Representative
- Respiratory Therapist Clinical Lead
- Social Worker
- Legal Counsel

APPENDIX A

Tracheostomy Process Algorithm



Revised November, 2010

Title: Pediatric / Neonatal Tracheostomy: Decision-Making and Pre-Tracheostomy Management	Date R1 24 May 2011	Page 7 of 10
--	--------------------------------------	------------------------

APPENDIX B

Community Resources for Patients with a Tracheostomy (& Ventilators)

- Home Care or CFS provides assistance and respite in the community. The service they provide must be nursing level for these patients. There is a limited number of hours and cannot be 100% reliable, as nurses/workers can be ill etc. and are difficult to replace at short notice.
- Home Care and CFS also available in cities/towns outside of Winnipeg. However, some areas do not have, or have very limited resources. Therefore, a child's feasibility of her returning to her own home outside of Winnipeg will depend on the resources available and accessibility to immediate care by knowledgeable medical professionals and accessibility to reliable transportation to a large centre.
 - *Of note – parents/patients may opt to go home, knowing of limited resources and inherent dangers and choosing to have the child at home living quality life with family.*
- In order to qualify for Children's Special Services (CSS) the individual needs to have physical or developmental delay.
 - CSS provides funding for equipment, transportation to medical appointments and help fund some nursing level respite.
 - Most training to care for these children is provided in hospital. There are limited resources for training and teaching in the community.
- United Referral Intake System (URIS) provides the funding to train and provide the special worker for a child with special needs at school. Collaborates with Manitoba Health & Education
 - When the child goes to school under "URIS" rules, they must have a trained Registered Nurse with them at all times. The rules are in the process of being revised to broaden this to Licensed Practical Nurses and Respiratory Therapists.
 - Children attending schools that are not in a school division per se: (i.e. Aboriginal community; Hutterite colony) are not provided with nurses or home care therefore, this becomes an issue for the child going to school (i.e. Mother or another "trained" adult needs to be with the child at "all" times).
- Resources on Aboriginal communities and Hutterite colonies are dependent on the community itself – no home care or Child & Family Services (CFS) available.

Other Resources Once an Adult

Of note: Respite/assistance does not need to be nursing

EIA – Employment Income Assistance; based on income

- Vocational rehab – for those with an IQ of >75; provides resources for living independently and finding a job

SLP – Supportive Living Program; for those with an IQ < 70

- Provide child/parent guidance for the adult world
- Help with substitute decision making
- Help with non-professional aid and transportation

LIRA – Living Independent Resource Centre

- Helps to organize self and family manage care
- Self and family managed care – funding from WRHA; only for adults or for children that need non-nursing respite.

Title: Pediatric / Neonatal Tracheostomy: Decision-Making and Pre-Tracheostomy Management	Date R1 24 May 2011	Page 8 of 10
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APPENDIX C

Psychosocial Assessment

Basic Social Work Assessment

Family composition:

- Who makes up the existing household?
- Who is the primary caregiver for the child(ren)?
- How are decisions made in the family?
- What is the quality of the relationships within the family?

Financial situation:

- Employment status, receiving provincial or band financial assistance?

Previous community social service involvement?

Previous experience with coping with illness or stressful situations?

Exploration of existing support network:

Informal support:

- Who helps out with babysitting, financial and other practical supports?
- What is the quality of the relationship with extended support network?
- Who can parent turn to for emotional support?
- What role does this support network play in how parent makes decisions i.e. are they impacted by the approval/disapproval of anyone in the support network?

Formal support:

- Is family connected with any community support programs/services and what is provided?
- Is family connected with a religious or spiritual community?
- Is there a role for any of the family's formal supports in parent's decision making and if so how would family like them to be involved?

Exploration of parents' understanding of present illness/medical situation

- Do they feel adequately informed?
- Do parents feel like they can ask questions?
- Are parents able to explain to other family members and is this a source of stress for them?

Exploration of Impact of Tracheostomy on Family and Support Network

- Does the family live outside Winnipeg? If yes,
 - Size of community?
 - What type of health care services are available?
 - What are the support service options for respite?
- Will tracheostomy necessitate the family to relocate to a larger setting?
 - If yes, what is the impact on the family's informal and formal support system?
 - Does the family have friends/family in the city?
 - Would any of their extended family relocate with them?
- As care for child with a tracheostomy is very specialized, who in the current support network would be able/willing to take on the responsibility of learning tracheostomy care and be available to provide practical support in the way they did previously?
- The responsibility of caring for a child with a tracheostomy usually means that at least one parent needs to be a stay at home parent.
 - How does this impact the family financially?
 - What is the impact for the primary caregiver on their other roles i.e. job/career identity, other roles outside the home with community clubs, sports, hobbies etc?

APPENDIX D

Tracheostomy Team Case Review Checklist

Medical indication:

- | | | |
|--|------------------------------|---|
| 1. Medical situation adequately defined. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Options thoroughly explored. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Pediatric Respiriologist consulted and agreed. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Surgeon consulted and agreed. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Adult Respiriologist consults (for patients > 14 years old). | <input type="checkbox"/> Yes | <input type="checkbox"/> No
<input type="checkbox"/> N/A |
| 6. PSCU Team informed. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 7. Family informed of situation. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 8. Community options explored and potential community placement location identified. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 9. All members of the health care team in agreement. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

Comments:

APPENDIX E

Pre-Tracheostomy Family Education Checklist

- Surgical risks
- Description of the surgery and the tracheostomy – pictures or see a tracheostomy
- Potential impact on child's health
- What to expect at home:
 - Constant care / type of caregivers
 - Risks of respiratory infection
 - Anticipated ventilation and oxygen needs
 - Stoma and tracheostomy care, suctioning etc.
 - Equipment and supply implications
 - Potential problems and troubleshooting
 - Resources available in their home community
 - Potential effects on their family
 - Living with external caregivers in the home, the effects of monitors and false alarms
- Review of the post-operative education process
- Consideration of pertinent questions to review with family:
 - What do you expect the tracheostomy to do for your child?
 - What kind of life do you see for your child? Will having a tracheostomy make that happen?
 - How do you see your life with your child having the tracheostomy?
 - What if you are unable to provide the necessary care?
 - Who will be your support? Who will be there not just now but in the future?
 - What kind of support from the health care system do you expect?
- Written materials provided to parents (if appropriate)