Caring for Children with Medical Complexity in the Community Setting

TELEHEALTH ROUNDS

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PGY 4 PEDIATRICS

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Acknowledgements

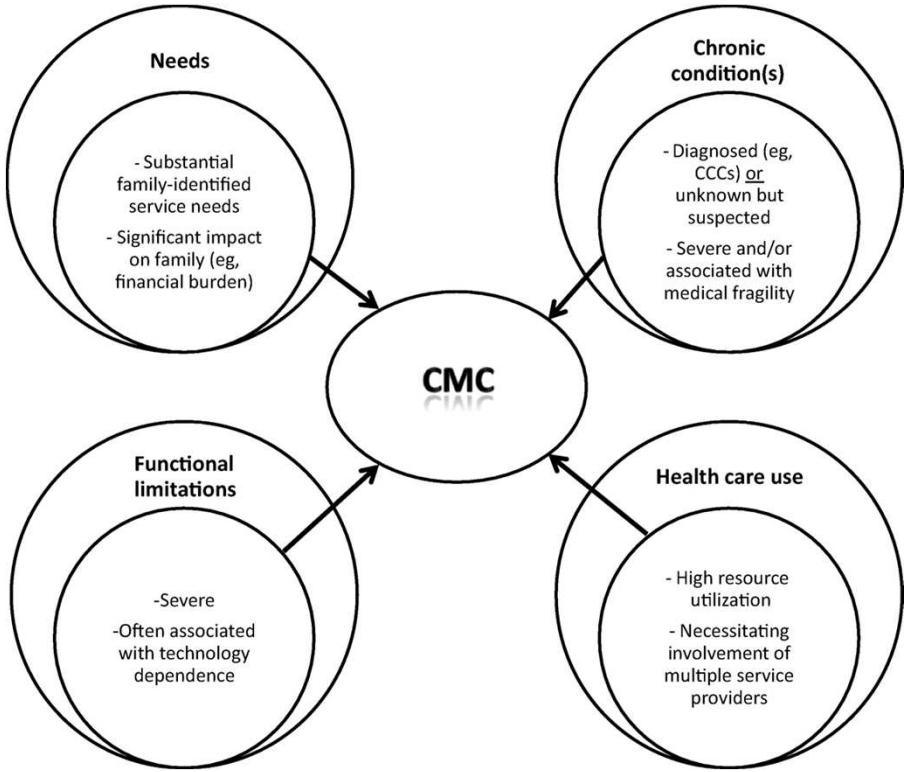
- Dr. Nathalie Major, Dr. Kheirie Issa, and Dr. Tobey Audcent (CHEO Complex Care Pediatricians)

Objectives

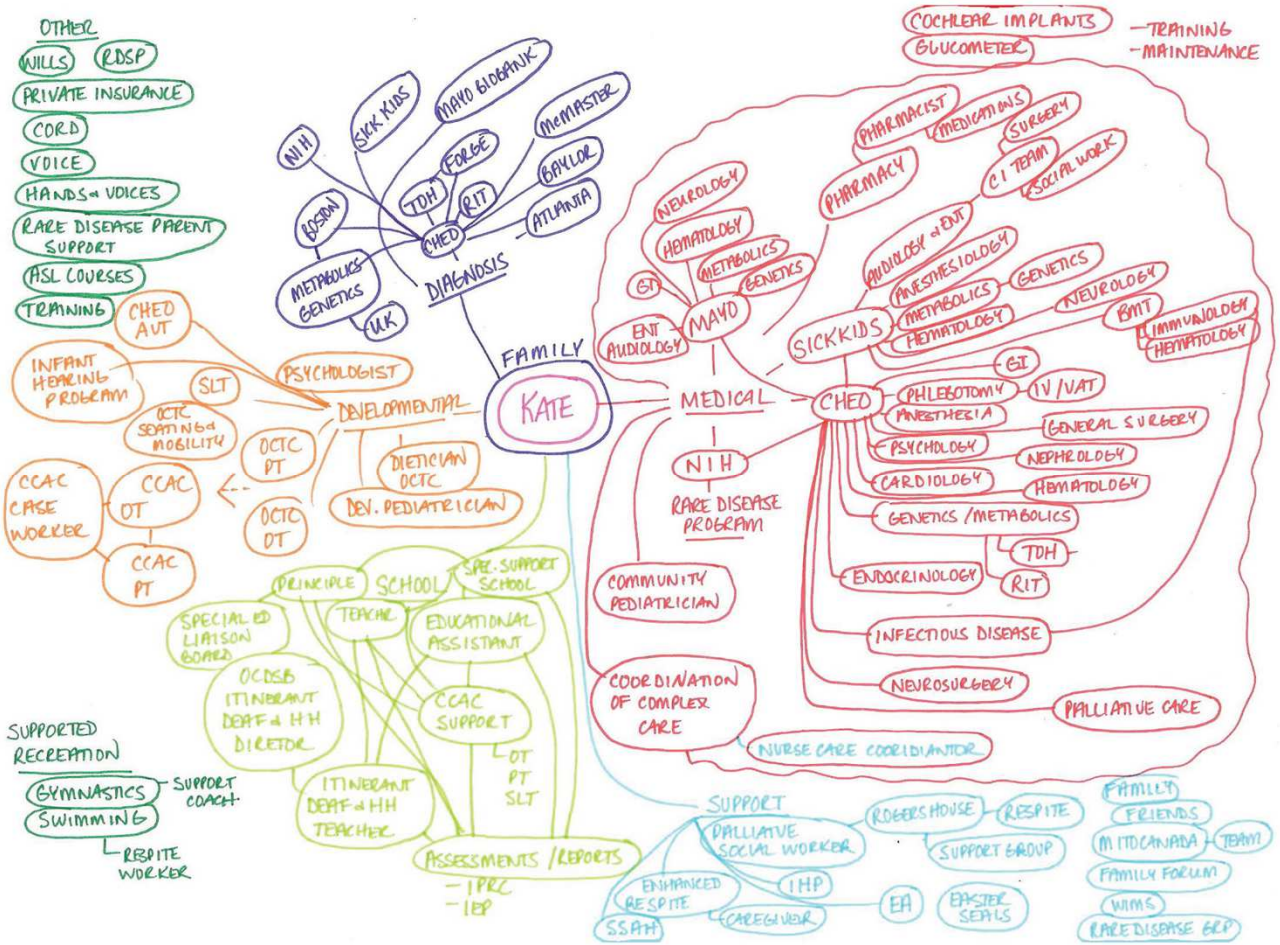
- Define and recognize "children with medical complexity" (CMC) in your practice
  - Identify challenges of caring for CMC in the community
- Review the roles of primary care providers for CMC
  - Health surveillance
- Provide clinical pearls regarding:
  - Tracheostomies
  - G-tubes
- Review how to support the transition of children with medical complexity to an adult care setting

Recognizing "Children with Medical Complexity"

Defining "Children with Medical Complexity"[1]



- **0.7% of all Canadian children account for 33% of pediatric health expenditures!**



Example of care map for a child with medical complexity[2]

Role of the Primary Care Provider for CMC[2,3]

- **"Individual primary care practices should be supported as the foundation of longitudinal, comprehensive care for CMC"**
  - Emerging clinics for CMC care coordination in tertiary centres
  - Single provider as designated care-coordinating entity

- Health maintenance and preventative care
- Development, psychosocial needs
- Medical management of chronic conditions (in consultation with subspecialty services)
- Planning goals of care (if applicable)

Health Maintenance[4,5]

- For the well child:

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Revised February 20, 2014
www.rourkebabyrecord.ca

Canadian Paediatric Society / Société canadienne de pédiatrie — The College of Family Physicians of Canada / Le Collège des médecins de famille du Canada — Dietitians of Canada / Les diététistes du Canada

Past problems/Risk factors: | Family history:

Rourke Baby Record: Evidence-Based Infant/Child Health Maintenance GUIDE III: 9–15 mos

NAME: _____ Birth Day (dm/yy) _____ M [ ] F [ ]

Gestational Age: _____ Birth Length: _____ cm Birth Wt: _____ g Birth Head Circ: _____ cm

DATE OF VISIT	9 months (optional)			12–13 months			15 months (optional)		
GROWTH[1] use WHO growth charts. Correct age until 24–36 months if < 37 weeks gestation	Length	Weight	Head circ.	Length	Weight (if BW)	HC (avg 47 cm)	Length	Weight	Head Circ.
PARENT/CAREGIVER CONCERNS									

For each ❑ item discussed, indicate "✓" for no concerns, or "X" if concerns

NUTRITION[1]	❑ Breastfeeding[2] Vitamin D 400 IU/day[3] *Formula feeding – iron-fortified preparation[4] (720–960 ml/24–32 oz/day[5])* ❑ No bottle in bed ❑ Cereal, meat/alternatives, fruits, vegetables ❑ Cow's milk products (e.g., yogurt, cheese, homogenized milk) ❑ No honey[6] ❑ Choking/safe foods[7] ❑ *Avoid sweetened juices/liquids* ❑ Encourage change from bottle to cup	❑ Breastfeeding[2] Vitamin D 400 IU/day[3] ❑ Homogenized milk (500–750 ml/16–24 oz/day[5]) ❑ Appetite reduced ❑ Choking/safe foods[7] ❑ *Avoid sweetened juices/liquids* ❑ Promote open cup instead of bottle ❑ *Inquire re: vegetarian diets[8]*	❑ Breastfeeding[2] Vitamin D 400 IU/day[3] ❑ Homogenized milk (500–750 ml/16–24 oz/day[5]) ❑ Choking/safe foods[7] ❑ *Avoid sweetened juices/liquids* ❑ Promote open cup instead of bottle ❑ *Inquire re: vegetarian diets[8]*
EDUCATION AND ADVICE Injury Prevention	❑ *Car seat optimal[9]* ❑ *Carbon monoxide/smoke detectors[10]* Childproofing, including: ❑ *Electric plugs/outlets*	❑ *Poisons[11]: PCC#[12]* ❑ *Hot water: <60°C/140°F safety[13]* ❑ *Falls (stairs, change table, unstable furniture/TV, no walkers)[14]*	❑ *Firearms safety[15]* ❑ *Pool fence[16]* ❑ *Choking/safe toys[7]*
Behaviour and Family Issues	❑ *Crying[17]* ❑ *Healthy sleep habits[18]* ❑ *Night waking[19]* ❑ Soothability/temperaments ❑ *High risk children/anxious home visit need[20]* ❑ Siblings ❑ *Parenting[21]* ❑ *Parental fatigue/depression[22]* ❑ *Family conflict/stress* ❑ *Child care/Return to work* ❑ *Family healthy active living/sedentary behaviour[23]* ❑ *Tobacco exposure[24]*		
Environmental Health	❑ *Second hand smoke[24]* ❑ *Sun exposure/sunscreen/insect repellent[25]* ❑ *Screen food if at risk[26]*		
Other Issues	❑ *Teething/Dental cleaning/Fluoride/Dentist[27]* ❑ *Inner ear/otitis/immunizations[28]*	❑ *Complementary/alternative medicine[29]* ❑ *Encourage reading[30]* ❑ No OTC cough/cold medicine[31] ❑ *Sunscreen[32]*	
DEVELOPMENT[33] (Inquiry and observation of milestones) Tasks are set after the time of normal milestone acquisition. *Absence of any tests suggests consideration for further assessment of development.* NB–Correct for age if < 37 weeks gestation	❑ *Looks for an object seen hidden* ❑ *Babbles a series of different sounds (e.g., baba, dadada)* ❑ *Responds differently to different people* ❑ *Makes coos/gestures to get attention or help* ❑ *Sits without support* ❑ *Stands with support when helped into standing position* ❑ *Opposes thumb and fingers when grasps objects* ❑ *Plays social games with you (e.g., note touching, peek-a-boo)* ❑ *Cries or shouts for attention* ❑ *No parent/caregiver concerns*	❑ *Responds to own name* ❑ *Understands simple requests, (e.g., Where is the ball?)* ❑ *Makes at least 4 consonant-vowel combination* ❑ *Says 3 or more words (do not have to be clear)* ❑ *Crawls or 'bum' shuffles* ❑ *Pulls to stand/walks holding on* ❑ *Shows distress when separated from parent/caregiver* ❑ *Follows your gaze to jointly reference an object* ❑ *No parent/caregiver concerns*	❑ *Says 5 or more words (words do not have to be clear)* ❑ *Picks up and eats finger foods* ❑ *Walks (always holding onto furniture)* ❑ *Shows fear of strange people/places* ❑ *Crawls up a few stairs/steps* ❑ *Tries to squat to pick up toys from the floor* ❑ *No parent/caregiver concerns*
PHYSICAL EXAMINATION An appropriate age-specific physical examination is recommended at each visit. Evidence-based screening for specific conditions is highlighted.	❑ Anterior fontanelle[34] ❑ Eyes (red reflex) ❑ Corneal light reflex/Cover-uncover test & inquiry[35] ❑ Hearing inquiry/screening[36] ❑ Hips[37]	❑ Anterior fontanelle[34] ❑ Eyes (red reflex) ❑ Corneal light reflex/Cover-uncover test & inquiry[35] ❑ Hearing inquiry/screening[36] ❑ Vocal stridor/sleep-disordered breathing[38] ❑ Teeth[39] ❑ Hips[37]	❑ Anterior fontanelle[34] ❑ Eyes (red reflex) ❑ Corneal light reflex/Cover-uncover test & inquiry[35] ❑ Hearing inquiry/screening[36] ❑ Vocal stridor/sleep-disordered breathing[38] ❑ Teeth[39] ❑ Hips[37]
PROBLEMS AND PLANS			
INVESTIGATIONS/IMMUNIZATION Discuss immunization pain reduction strategies[40]	❑ *If lifelong positive mother check HIV antibodies and lifts[41] (at 9 or 12 months)* ❑ *Hemoglobin (if at risk)* ❑ Record Vaccines on Guide V		❑ Record Vaccines on Guide V
Signature			

Family History, Risk Factors, Allergies

Preventive Care Visits: Ages 6,7,8,9
The Greig Health Record
(visits in this age group are recommended every one to two years)

Name:
Date of Birth:

			Age 6	Age 7	Age 8	Age 9
Date						
Measurements (use WHO growth charts)	Wt	BMI				
	Ht	BMI percentile				
Psychosocial history and Development	• School & Activities					
	• Peer relationships					
	• Family relationships					
	• Body changes					
	• Menstrual issues ♀					
Nutrition *	• Healthy choices / snacks / junk-food					
	• Supplements / CAM					
	• Body Image / Dieting					
Education & Advice: Behaviour and Family Issues	• **Physical Activity**					
	• Electronic Media – TV / Internet /Hearing Protection					
	• Sleep Issues					
	• Effective Discipline					
Injury Prevention & Safety	• **Helmet safety**					
	• **Vehicle Safety – Seatbelts, Booster Seats**					
	• *Violence* & **Firearms**					
	• Trampoline Safety					
	• Water Safety					
	• *Sun Safety*					
Other	• Environmental Hazards – incl. **Second Hand Smoke**					
	• *Smoke Detectors*					
	• Other Safety Topics					
	• Substances & Addictions					
	• Abuse					
	• **Dental care, fluoride**					
Specific Concerns						
Examination	Blood Pressure					
	Head & Neck					
	Visual Acuity (L) (R)					
	CVS					
	Chest					
	Back					
	Abd					
	GU					
	Sexual Maturity Rating					
	Skin					
Assessment Immunization Medications ©A.Greig 2016	Update immunizations: **DTaP-IPV (age 4-6)** **MMR (2nd dose by age 6)** **HPV (ages 9 and older)** **Varicella vaccine-2 doses (12mos to 12 years)** Discuss influenza vaccination Consider TB test Signature					

Strength of Recommendations: Bold = Good; Italics = Fair; Plain Text = consensus or inconclusive evidence

Disclaimer: Given the evolving nature of evidence and changing recommendations, the Greig Health Record is meant to be used as a guide only.

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Selected Guidelines and Resources are found on accompanying pages

For children with medical complexity[6]:

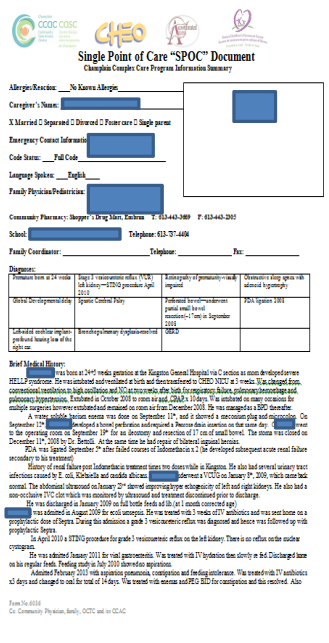
HEENT	Eyes	Regular eye exams? Services for visual impairment Corneal abrasion risk
	Ears	Hearing screened? Sign language, adaptive technology? Hearing impaired supports?
	Mouth	Dental hygiene Dentist/Orthodontist care and cleaning Dental insurance
MSK	Hips	Clinical/radiographic Surveillance
	Spine	Clinical/radiographic Surveillance
ENDO	Bone Health	Fracture history Investigations – labs, imaging Intervention: Ca, Vitamin D, bisphosphanates
SYMPTOMS		Pain/Irritability
		Sleep disturbance
		Other
MEDICATIONS		General review – still indicated? Dosing?
		Prescriptions, renewals, orders
		Routine monitoring
		Side effects, interactions
		CAM
		Special funding required

	Thyroid	Screen if indicated	
DERM		Pressure sores Rashes	
HEME			
ID	Immunizations	Routine Additional	

		Dosing?	
		s	
		port	
		tion	

Tools for Care Coordination[6]

Care Plans – "Single Point of Care"



Single Point of Care "SPOC" Document
Champlain Complex Care Program Information Summary

Allergies/Reaction: ___No Known Allergies___

Caregiver's Name: [redacted]

X Married ☐ Separated ☐ Divorced ☐ Foster care ☐ Single parent

Emergency Contact Information: [redacted]

Code Status: ___Full Code___

Language Spoken: ___English___

Family Physician/Pediatrician: [redacted]

Community Pharmacy: Shoppers Drug Mart, Embrun T: 613-443-3989 F: 613-443-2365

School: [redacted] Telephone: 613-737-4404

Family Coordinator: _____ Telephone: _____ Fax: _____

Diagnoses:

Problems born at 24 weeks	Stage 3 vesicoureteric reflux (VUR) left kidney—STING procedure April 2010	Autosepsis of prematurity—made repaired	Obstructive sleep apnea with adenoid hypertrophy
Global Developmental delay	Epastic Cerebral Palsy	Preferred bowel—moderate partial small bowel constipation(~17cm) in September 2011	PDA ligation 2008
Left sided cochlear implant- profound hearing loss of the right ear	Bronchopulmonary dysplasia-on trial	GERD	

Brief Medical History:

[redacted] was born at 24+5 weeks gestation at the Kingston General Hospital via C section as mom developed severe HELLP syndrome. He was admitted and ventilated at birth and then transferred to CHEO NICU at 3 weeks. He was changed from conventional ventilation to high oscillation and NO as recovery after both for respiratory failure, pulmonary hemorrhage and pulmonary hypertension. Extubated in October 2008 to room air and CPAP x 10 days. He was intubated on many occasions for multiple surgeries however extubated and remained on room air from December 2008. He was managed as a SPOC thereafter.

A voiding cystogram enema was done on September 11th, and it showed a meconium plug and megacolon. On September 12th [redacted] developed a bowel perforation and required a Penrose drain insertion on that same day. [redacted] went to the operating room on September 18th for an ileostomy and resection of 17 cm of small bowel. The enema was closed on December 11th, 2008 by Dr. Bertolli. At the same time he had repair of bilateral inguinal hernias.

PDA was ligated September 5th after failed courses of Indomethacin x 2 (he developed subsequent acute renal failure secondary to his treatment).

History of renal failure post Indomethacin treatment times two doses while in Kingston. He also had several urinary tract infections caused by E. coli, Klebsiella and candida albicans. [redacted] underwent a VCUG on January 7th, 2008, which came back normal. The abdominal ultrasound on January 27th showed improving hyperechogenicity of left and right kidneys. He also had a non-occlusive IVC clot which was monitored by ultrasound and treatment discontinued prior to discharge.

He was discharged in January 2009 on full bottle feeds at 6lb (at 1 month corrected age).

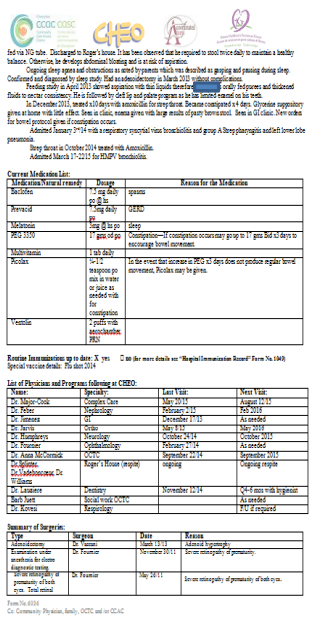
[redacted] was admitted in August 2009 for scoli untoxpin. He was treated with 3 weeks of IV antibiotics and was sent home on a prophylactic dose of Septra. During this admission a grade 3 vesicoureteric reflux was diagnosed and hence was followed up with prophylactic Septra.

In April 2010 a STING procedure for grade 3 vesicoureteric reflux on the left kidney. There is no reflux on the contrast cystogram.

He was admitted January 2011 for viral gastroenteritis. Was treated with IV hydration then slowly re fed. Discharged home on his regular feeds. Feeding study in July 2010 showed no aspiration.

Admitted February 2011 with aspiration pneumonia, constipation and feeding intolerance. Was treated with IV antibiotics x3 days and changed to oral for total of 14 days. Was treated with enemas and PEG BID for constipation and this resolved. Also

Form No 0106
Cc: Community Physician, family, OCTC and/or CCAC



fed via NG tube. Discharged to Roger's house. It has been observed that he required to stool twice daily to maintain a healthy balance. Otherwise, he develops abdominal bloating and is at risk of aspiration.

Ongoing sleep apnea and obstructions as noted hypoxemia which was described as gasping and pausing during sleep. Confirmed and diagnosed by sleep study. Had an adenoidectomy in March 2010 without complications.

Feeding study in April 2010 showed aspiration with thin liquids therefore [redacted] orally fed purees and thickened fluids to nectar consistency. He is followed by Gerd Sp and palate program as he has unusual enamel on his teeth.

In December 2010, treated x10 days with amoxicillin for strep throat. Became constipated x 4 days. Glycerine suppository given at home with little effect. Seen in clinic, enema given with large results of pasty brown stool. Seen in GI clinic. New orders for bowel protocol given if constipation occurs.

Admitted January 2nd 14 with a respiratory syncytial virus bronchiolitis and group A Strep pharyngitis and left lower lobe pneumonia.

Strep throat in October 2014 treated with Amoxicillin.
Admitted March 17-2015 for RSV bronchiolitis.

Current Medication List:

Medication/Natural remedy	Dosage	Reason for the Medication
Baclofen	7.5 mg daily po @ hs	spasms
Prevacid	7.5mg daily po	GERD
Melatonin	3mg @ hs po	sleep
PEG 3350	17 gms oid po	Constipation—If constipation occurs may go up to 17 gms Bid x3 days to encourage bowel movement.
Multivitamin	1 tab daily	
Picolax	½-1/2 teaspoon po mix in water or juice as needed with for constipation	In the event that increase in PEG x3 days does not produce regular bowel movement, Picolax may be given.
Ventolin	2 puffs with aerochamber PRN	

Routine Immunization up to date: X yes ☐ no (for more details see "Hospital Immunization Record" Form No. 1040)
Special vaccine details: Flu shot 2014

List of Physicians and Programs following at CHEO:

Name:	Specialty:	Last Visit:	Next Visit:
Dr. Major-Cook	Complex Care	May 2012	August 12-12
Dr. Peter	Nephrology	February 2-12	Feb 2016
Dr. Samson	GI	December 17-13	As needed
Dr. Jarvis	Urine	May 8-15	May 2016
Dr. Humphreys	Neurology	October 24-14	October 2015
Dr. Fournier	Ophthalmology	February 27-14	As needed
Dr. Anna McCormick	OOTC	September 22-14	September 2015
Dr. Mohsin, Dr. Chakhoumoune, Dr. Williams	Roger's House (respite)	ongoing	Ongoing respite
Dr. Lambert	Dentistry	November 12-14	Q4-6 mos with hygienist
Beth Jett	Social Work OOTC		As needed
Dr. Kovesi	Respiology		FU if required

Summary of Surgeries:

Type	Surgeon	Date	Reason
Adenoidectomy	Dr. Vaman	March 15-13	Adenoid hypertrophy
Examination under anesthesia for chronic diagnostic testing	Dr. Fournier	November 10-11	Severe enteropathy of prematurity
Inferior enteroplasty or prematurity of both eyes. Total retinal	Dr. Fournier	May 20-11	Severe enteropathy of prematurity of both eyes.

Form No 0106
Cc: Community Physician, family, OCTC and/or CCAC

Family-Focused Team Meeting Summary Form

Action Items	Discussion	Action Required	Person Responsible for Action	Date Completed
Dystonic Spasms	Dr. Macklin see value in [redacted] seeing Dr. Humphreys annually and to have plan re: spasticity and dystonia management especially when [redacted] is unwell. Parents shared that an increase in baclofen when he unwell decreased his spasms.	Annual visit to Dr. Humphreys to assess baclofen and dystonic spasms. Also approach Dr. Anna MacCormick for spasticity management	Dr. Major-Cook Dr. Macklin	

Medical Roadmap

Date of assessment/visit	Every 3-6 months: 1. Dr. Major q 3months alternating with Dr. Huot. 2. Dental q 4mos. 3. height, weight and head circumfrence q 6 mos 4. Vitals q visit. 6. Dr. Macklin	Every Year: 1. Ophthalmology 2.Nephrology 3. Renal ultrasound yearly 4.Neurology 5.Orthopedics 6. ECG 7. CBC diff, cap gas, bun, reatinini, cystatin C, lytes, venous gas, Ca, Mg, Phospate, urinalysis calcium and creatinine ratio.	Every 1-5 Years: 1.Bone health at 8-9 years of age. Ca, Mg Phos, AlkPhosphate, Vit D, PTH, glucos, cholesterol, triglycerides (fasting)

Clinical Pearls for Medical Technology

TROUBLESHOOTING TRACHEOSTOMIES AND G-TUBES

Tracheostomies – Main Indications[6]

Airway Patency and Protection

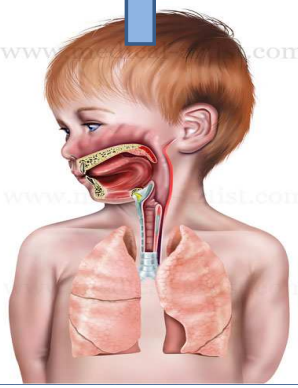
- Reduced or absent airway protective reflexes
- Airway/Facial Trauma
- Safe airway for procedures

Bypass Airway Obstruction

- Craniofacial and laryngeal malformations
- Subglottic Stenosis
- Tracheomalacia
- Airway Tumors (hemangiomas,etc.)
- Vocal Cord Paralysis

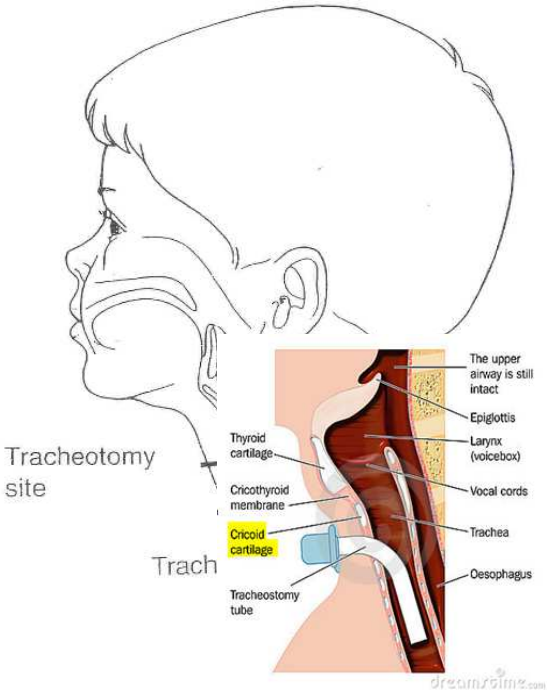
Long Term Ventilation

- Pulmonary disease
- Central respiratory drive
- Congenital heart disease
- Neuromuscular hypoventilation



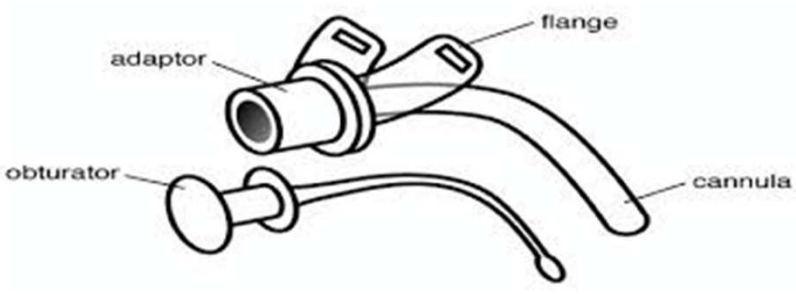
Alignment and Position[7-11]

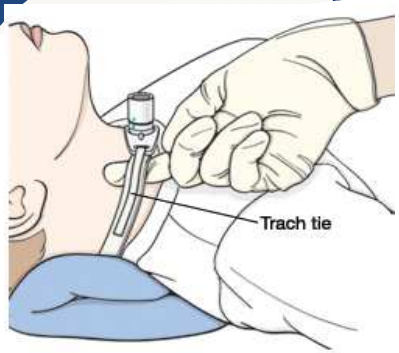
- Midline position
- Below cricoid cartilage
- Extends >2cm beyond stoma
- Ends 1-2cm above carina



Tracheostomy Tube Change[6]

- Tracheostomy tube inserted immediately using obturator
  - Obturator removed <u>immediately</u>
- Tracheostomy tube secured with trach ties via the flange





Trach Assessment in the Office: "TRACHEA"[8-11]

- **T**hickness of secretions; **T**echnique of suctioning
- **R**edness (bloody secretions); **R**edness of skin
- **A**pparent granuloma; **A**lignment
- **C**olour and odour of secretions
- **H**umidity
- **E**ating and speaking
- **A**BC management skill review, emergency kit

Skin Assessment: Redness at Stoma Site[8-11]

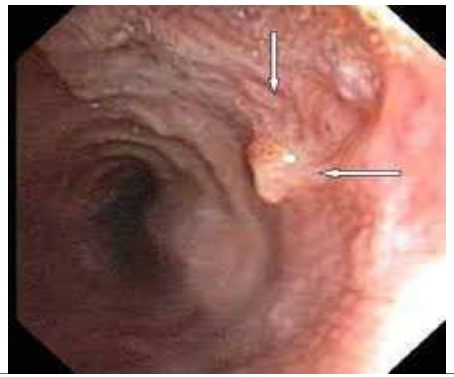
- **?Irritant/contact dermatitis**
  - Saliva, secretions, drooling, emesis
  - Loose-fitting trach ties
  - Sweating
- **?Bacterial cellulitis**
  - Erythema and swelling, tenderness to palpation
- **?Candidal infection**
  - Beefy red, satellite lesions

Redness at Stoma Site – Management Pearls[8-11]

- Change trach ties every 24h or whenever soiled
- Assess if ties are too tight (one finger rule)
- Keep area dry; no petroleum based agents
- For ?stoma site infection → swab for C&S, fungal culture
  - Local limited infection - topical
  - Purulent discharge, resp symptoms – oral antimicrobials
  - Empiric coverage for MSSA, S. Pyogenes, C. Albicans

Granuloma[8-11]

- Pink, moist, "cauliflower-like" tissue; bleeds easily
- Tissue fibrosis caused by:
  - Friction, repeated micro-trauma
  - Infection
  - Stasis of secretions
- Complications:
  - Tube obstruction
  - Tube dislodgement
  - Bleeding



Granuloma – Management Pearls[8-11]

- Check alignment with XR
- Assess if trach ties too loose/tight
- Keep area dry
- ENT consultation typically required
  - If external: topical corticosteroid 0.5-1% for 3-5 days to external visible stoma
    - Silver nitrate dressings by ENT
  - If internal: managed by ENT (antibiotic/steroid drops, trach change)

Bloody Secretions[8-11]

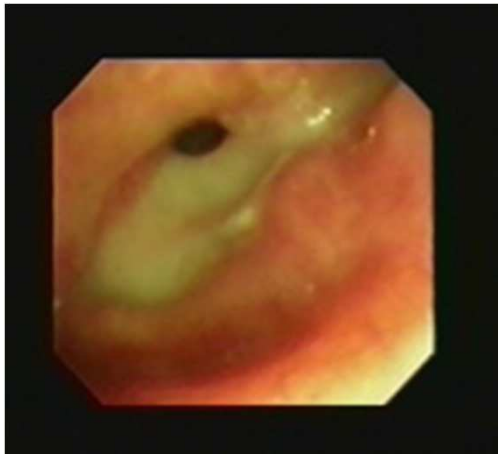
- **Brown secretions?**
  - Likely old bleeding; requires close monitoring and medical assessment/ENT consult if persistent.
- **Blood-tinged secretions?**
  - ?Local suction trauma
  - Requires urgent medical assessment
- **Bright red blood?**
  - ED assessment immediately with ENT consultation
  - Erosion through brachiocephalic artery is a rare but life-threatening complication

Bloody Secretions – Management Pearls[8-11]

- Review suction technique; ensure sufficient humidity
  - Avoid deep suctioning
  - Measure suction catheter (less than length of tube)
- Consider Pulmicort nebs BID or TID x few days (in consultation with ENT)
- Bronchoscopic evaluation by ENT if large amounts of bleeding

Change in Secretions[8-11]

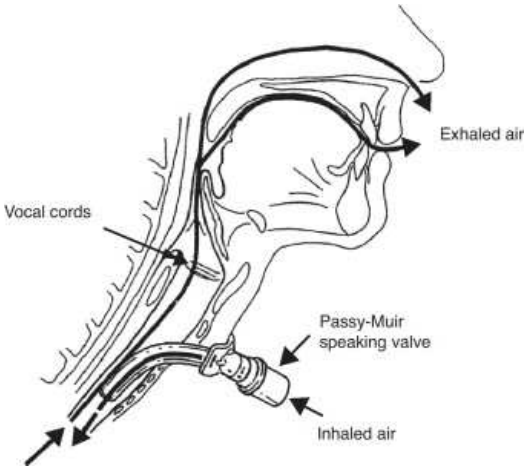
- **Purulent (yellow/green) secretions with strong odour?**
  - Ddx: viral infection, bacterial tracheitis, pneumonia
  - Evaluate for fever, increased RR/FiO2?
  - Send for virology, C&S +/- CBC+diff, CXR, cap gas
  - Review previous cultures to determine antibiotic coverage
    - Consider gram negative rod (*Pseudomonas)* coverage
  - *Small amount without odour may be normal in early AM



- **Thicker secretions?**
  - Consider inadequate hydration/humidity, old tracheostomy tube
  - *Thicker secretions also common upon waking

Eating and Speaking with a Tracheostomy[6]

- Swallowing can be affected
  - Trach tethers trachea in place – can't move up when swallowing
  - Directly in front of esophagus – feels like a "lump" in the throat
  - Aspiration risk
- Speaking valve (Passy Muir) commonly used



Tracheostomy – Daily Care[6]

Do's

- Bathing with supervision in 1-2 inches of water
- Showers in older children

Don'ts

- Swimming
- Contact sports
- Avoid pet hair, dust, fuzzy toys, small objects, sandbox

Emergency Trach Kit[6]

Emergency Kit

- ❑ *Replacement Tracheostomy tube*
  - *1 same size*
  - *1 size smaller*
- ❑ *Suction equipment and suction catheter*
- ❑ *Manual resuscitation bag*
- ❑ *Swedish nose*
- ❑ *Extra tracheostomy tube ties*
- ❑ Scissors, gauge, saline, syringe, etc.
- ❑ gloves (optional)

Families are encouraged to include:

- ✓ *Their "Emergency Phone List"*
- ✓ *A brief medical history of their child's condition*

Approach to Respiratory Distress in the Office : ABC's[6]

- Ensure tracheostomy tube is in situ
- Assess for airway obstruction (mucous, foreign body)
- Suction → instill saline, suction again
- Change tracheostomy tube
- Manual ventilation with resuscitation bag and oxygen
- Call EMS
- Consider other causes of respiratory distress:
  - Bronchospasm
  - Granuloma
  - Aspiration
  - Infection

Gastrostomy[6,19]

- Tube inserted through abdomen directly into stomach
- Gastrostomy = surgically created opening in stomach (stoma)
- Informed decision-making for choosing a device for long-term enteral feeding is essential →

REVIEW

A guide to the management of common gastrostomy and gastrojejunostomy tube problems

Joanna Soscia NP-Paeds MEd MN[1], Jeremy N Friedman MB ChB FRCPC[1,2]

J Soscia, JN Friedman. A guide to the management of common gastrostomy and gastrojejunostomy tube problems. Paediatr Child Health 2011;16(5):281-287.

Un guide pour la prise en charge des problèmes courants liés aux sondes de gastrostomie et de gastrojéjunostomie

Types of G-Tubes[6]

- Long tubes: PEG, pig-tail, Foley

- Low profile tubes or buttons: balloon (Nutriport; Mickey) vs non-balloon

Pulled or Broken G-Tube[12-16]

- Following initial tube insertion, 6-8 weeks for tract to become established
- Stoma **<u>can begin closing 1-4 hours after removal of tube</u>** (even if established)
- Insert replacement tube ASAP!
  - Families should have replacement (Mickey) on hand
  - Can use Foley catheter temporarily
  - If <2 weeks old → ED visit, Gen Sx consult
  - If <8-12 weeks → insert Foley or button, inflate and restart feeds after aspirating gastric contents
  - **DO NOT attempt to reinsert replacement GJ or J tube**

G-tube Obstruction[12-16]

- Feeding tubes should be flushed:
  - Pre- and post-feeds
  - Before, between, after meds
  - Every 4 hours if continuous feeds
- Possible causes of obstruction:
  - Meds not properly dissolved
  - Meds incompatible with tubes
  - Inadequate flushing
  - Tube malposition

Medications that can block G-tubes
Clarithromycin, ciprofloxacin
Magnesium oxide
Kayexalate
Levocarnitine
Sevelamer (phosphate binding drug)

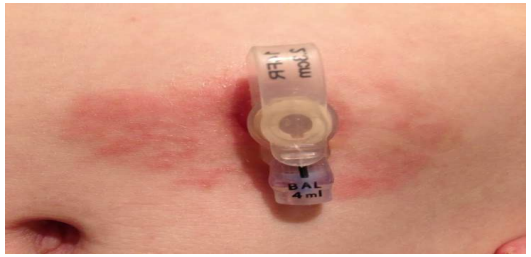
Management steps to unplug G-tube:
1) Check for kinks, ensure clamp is open
2) Flush with warm water or carbonated water via small syringe (higher pressure)
3) Push and pull plunger to move liquid in and out of feeding tube
4) Change extension
5) Tube replacement

G-Tube Granuloma[12-16]

- Common in first 2-3 months post-insertion
- Dark pink, moist, fleshy, 'cauliflower-like'
- May have yellow discharge → not suggestive of infection
- Management:
  - Keep site free of moisture, stabilize tube
  - Silver nitrate
  - Hydrocortisone cream 0.5-1%, 3-5 day course

Redness at G-Tube Site[12-16]

- **?Infection at GT site**
  - Spreading erythema, tenderness, warmth, purulent discharge +/- fever
  - Swab if drainage for C&S
    - Staphylococcus, streptococcus
  - Mx: PO Keflex, clean with saline
- **?Irritant dermatitis**
  - From gastric acid; friction from mobile tube; reaction to tape



GT Migration, Outlet Obstruction

- Part of the GT lodged in pylorus/duodenum → partial/complete obstruction

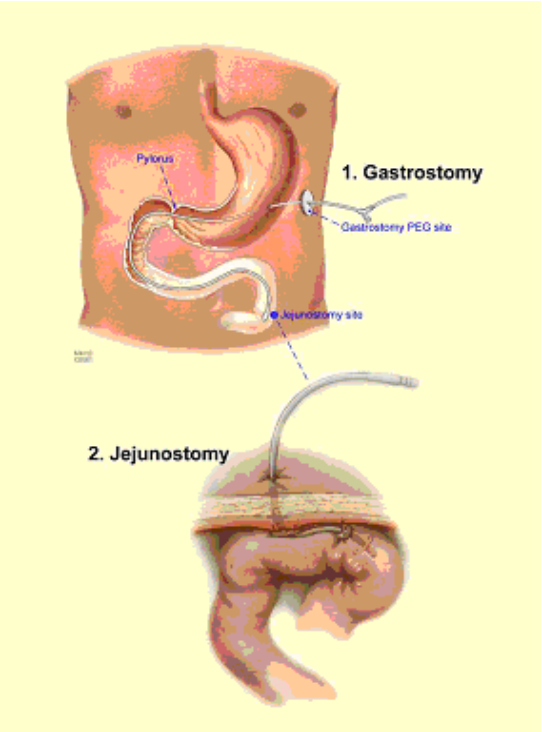
- Presentation:
  - Signs of obstruction - feed intolerance, vomiting, irritability
  - Sudden onset cough
  - Decrease in tube length (external part)

- Management:
  - Stop feeds
  - ED visit +/- consult Gen Sx
  - UGI to confirm dx (GT study)

- Prevention:
  - Maintain tube placement
  - Check external length

GJ Tube – Feeding in the Jejunum[12-16]

- **<u>Indications for jejunal feeding:</u>**
  - Severe GERD with FTT
  - Poor gastric motility → high risk of aspiration of gastric contents
  - Inability to have GT (i.e. pyloric outlet obstruction)
- GJ feeds must be given via pump over 18-24h
  - Jejunum cannot tolerate rapid/large infusions
  - Diaphoresis, tachycardia, cramping, diarrhea

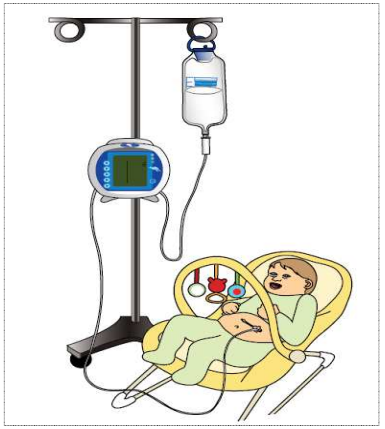


Enteral Feed Complications[6]

Complication	Cause	Prevention/Treatment
Diarrhea	Rapid increase in amount of feed Excessively rapid infusion rate Feed temperature too cold Hyperosmolar feedings (>300 mOsm) Lactose intolerance Fat malabsorption Antibiotic therapy or medications	Observe adaptation phase Reduce infusion rate Increase feeds to room temperature Start with isotonic feeding solution Lactose-free/low-fat MCT-containing diet Review medications
Nausea, vomiting	Excessively rapid infusion rate	Reduce infusion rate
Regurgitation, aspiration	Gastric retention	Reduce infusion rate, use duodenal tubes, incline patient during feed administration
Constipation	Inadequate fluid intake	Increase fluid intake, check fluid balance

Daily Activities with a G-Tube[6]

- Swimming allowed 2 weeks after insertion
- Baths allowed once stoma healed
  - 7 days after initial tube insertion
- No restrictions on positioning – prone vs supine
  - Should assume sitting/upright position when connected to feeding pump
- No restrictions for most sports and physical activities (unless high risk of breaking or pulling on tube)



Transition of CMC to Adult Care

Barriers to Successful Transition[17]

Patient-Related Barriers
Autonomy and self-care management
Relationships with existing pediatric providers
Financial resources and insurance coverage
Developmental delay, literacy
Equipment accessibility

Systemic Barriers
Lack of allied health/multi-disciplinary support in adult care environment
Engaging adult providers skilled in working with complex youth
Inadequate remuneration for adult providers for complexity of work
Communication with adult providers in transfer of care

Key Elements of Health Care Transition[17,18]

got transition

Transitioning Youth to An Adult Health Care Provider

Six Core Elements of Health Care Transition 2.0

- Transition Policy
- Transition Tracking and Monitoring
- Transition Readiness
- Transition Planning
- Transfer of Care
- Transfer Completion

POSITION STATEMENT

Transition to adult care for youth with special health care needs

M Kaufman, J Pinzon; Canadian Paediatric Society
Adolescent Health Committee
Paediatr Child Health 2007;12(9):785-8
Posted: Nov 1 2007 **Reaffirmed:** Feb 1 2016

Goals of transition:

- Adolescent involvement in management of condition
- Adolescent and family understanding of condition
- Understanding personal potential for activity, education, recreation, vocation
- Completion of adolescent developmental tasks
- Attainment of self-esteem, self-confidence

Enhanced Transition Process for CMC

- **12-14 year of age:**
  - Identify family physician
  - Life skills and autonomy, educational goals, vocational goals
    - Neuropsychiatric evaluation completed?
  - Physical activity
  - Nutrition
  - Sexual development (?genetic counseling for future pregnancy)
  - Insurance and RDSP plans

Enhanced Transition Process for CMC

- **14-16 years:**
  - Health card renewal (16 yo in Ontario)
  - Transportation plans – any contraindications to driving?
  - Finances – bank account (joint)
  - Consultation with lawyer regarding decision-making, autonomy, capacity, POA/Guardianship
  - Rehab consult if mobility equipment needed
  - Identify respite resources if needed
  - Discuss an emergency plan for acute illness (in the adult system)

Enhanced Transition Process for CMC

- **16-18 years:**
  - Identify adult specialists
    - Ensure first appointments are made and attended
  - Meet with PCP: provide care plan documents, roadmaps
    - Ensure availability to meet with PCP up to 2 yrs after transfer
  - Ensure referral to Service Coordination (complete DSO, ODSP forms by 18 years of age)

Questions?

- vchan@cheo.on.ca

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