

PROGRAM REPORT

THE COMPLEX CARE SERVICE

at the Montreal Children's Hospital, McGill University Health Centre

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PROGRAM SUMMARY

The Complex Care Service (CCS) offers multidisciplinary comprehensive pediatric care for children with significant degrees of medical complexity, focusing on children with multiple care needs, technology dependence and fragility. Families receive the services of a dedicated nurse care coordinator, consultant pediatrician and allied health professionals. In addition to scheduled inpatient and outpatient consultations and clinic visits, the CCS team also offers: a daily urgent care clinic and a 24/7 on call service. Program innovations include a: complex care clinical fellowship, standardized curriculum for pediatric postgraduate trainees, home/community visitation program and a collaborative website of evidence-based standardized homecare practices.

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PROGRAM DESCRIPTION

More than 50 years ago, a small avant-garde group of health care professionals based at the Montreal Children's Hospital (MCH) observed what seems obvious today:

- 1) that prolonged hospitalizations were detrimental to children in many ways,
- 2) that parents and caregivers were willing and capable of caring for their children with complex needs in their own homes and
- 3) that comprehensive and coordinated health care was crucial for these special children.

Starting in 1964, the Complex Care Service (CCS) began to transition children from hospital to home-based care and an era of innovation began. Children with rheumatological diseases, neuromuscular conditions and hematological disorders were amongst the first served by the program, which was originally called the "Homecare Program", a nickname which remains in use. Through teaching and hands-on practice, parents were enabled to look after their child's needs. Sparse community services were accessed and coordinated for families; outreach education became an important CCS objective. From the earliest days, nurse care coordinators

and empowered parents have formed the basis of CCS.

While the population served by the MCH CCS has evolved with changing demographics of children with medical complexity (CMC), the service has retained the original mission which is to provide safe, effective and family-centered care to children with complex medical needs, in their own home environment. Our multidisciplinary team believes that caregivers, and most children, should participate in the processes of health care assessment, therapy implementation, preventive efforts and evaluation. Our goals are to:

1. improve the quality of life of children with complex medical conditions by
 - a. maintaining and encouraging child/family autonomy
 - b. minimizing the physical and psychosocial impacts of intensive home care on the child and family
 - c. encouraging joy and development of every child
2. decrease unscheduled hospitalizations and emergency visits
3. effectively coordinate the needs of the child/family with home, community, and hospital services.

SERVICES PROVIDED

PATIENT CARE SERVICES: Today, the CCS serves approximately 500 children, with an annual turnover of 75-100, with a combination of highly complex conditions, medical fragility and dependence upon

technology (Table 1). Through a standard consultation procedure, patients are referred from both inpatient and outpatient medical and surgical services at our institution. Referrals are also received from community providers and other hospitals in Quebec.

Location	Montreal Children's Hospital, McGill University Health Centre
Staffing	<p>Core Staff includes:</p> <ul style="list-style-type: none"> ● 5 Pediatricians (each attending 5-15 weeks year in CCS + scheduled visits clinics) ● 1 FTE Clinical Manager ● 1 FTE Assistant Nurse Manager ● 1 FTE Advance practice nurse ● 7 FTE Nurse coordinators ● 1 FTE Discharge Coordinator ● Nurse Educator ● Allied health support
Patient Demographics	<p>Patients 0 to 18 years of age with the following characteristics:</p> <ul style="list-style-type: none"> ● Chronicity ● Complexity ● Fragility ● Technology dependency/high intensity care needs grouped as follows: <ul style="list-style-type: none"> ○ Neuromuscular conditions ○ Tracheostomy/Home Ventilation ○ Bronchopulmonary Dysplasia on home oxygen support ○ Home parenteral nutrition ○ Long-term enteral nutrition ○ Immunocompromised ○ Multiplex- children with rare genetic/neurological/metabolic conditions with multiple co-morbidities ○ Heart transplant ○ Thalassemia ○ Congenital hemostasis disorders
Key Services	<ul style="list-style-type: none"> ● Designated nurse coordinator/ pediatrician for longitudinal care ● Daily urgent care clinic ● Scheduled comprehensive multi-disciplinary visits ● 24/7 on-call nurse-pediatrician team ● Consultations (inpatient and outpatient) ● Home visits
Teaching Services	<ul style="list-style-type: none"> ● Elective (medical students) ● Clinical Rotation (PGY2, PGY4) ● Clinical Fellowship (one year) ● International visitors (2-3 per year)
Education Innovations	<ul style="list-style-type: none"> ● <i>Complexcareathomeforchildren.com</i> ● National curriculum for pediatric postgraduate trainees

Table 1. Snapshot of CCS at MCH

Scheduled, comprehensive consultative care is provided by a dedicated team of nurses and physicians, along with allied health partners. In addition, urgent care visits are offered daily through a medical day hospital clinical setting. Acutely ill children may be seen as needed, with assessments and interventions, preventing or decreasing the duration of both emergency department visits and inpatient hospitalization. This, along with a 24/7 on call service, is considered by families as a “lifeline”. By design, the CCS program is situated adjacent to the general medical day hospital; sharing administrative and some clinical services.

Proactive care plans for predictable decompensations (eg. ketotic hypoglycemia, seizures, respiratory infections) are developed with families, subspecialists and the CCS team such that parents are empowered to care for their children safely at home as much as possible (Figure 1). These care plans are frequently structured as colour coded schemes: green light plans for usual care days, yellow light for moderate decompensation and red light for more severe illness. For children with more complex algorithms, additional plans are made for Emergency Department and inpatient care (eg. ongoing seizures despite

home use of vagal nerve stimulator, intranasal midazolam, etc.). The care plans are part of the electronic medical record.

Hôpital de Montréal pour enfants / Centre universitaire de santé McGill / Montreal Children's Hospital / McGill University Health Centre

CCS Action Plan for Parents / Caregivers

Name: XXXX DOB: Weight: XX kg Date: June 12, 2019
Goals of Care: Minimize/eliminate hypoglycemia and borderline hypoglycemia
CCS Daytime: ##### **CCS ON CALL:** ##### and ask to speak with the on-call nurse for CCS
Alerts: PORT, possible underlying mitochondrial disorder

**GREEN ZONE
I AM WELL!**

XXXX is feeling well AND does not have a fever. She is eating normally. Her blood glucose (BGs) have been stable and above 3.5 for the majority of the day and night. Continuous blood glucose monitoring via sc monitor.
Serum BG 3.5 or greater (less than 13)
DAYTIME: Eats by mouth as per usual; Continuous blood glucose monitoring; under the surveillance of a mature adult knowledgeable in the identification and treatment of hypoglycemia.
SLEEP: Continuous GT feed at 35 ml/hr = Glucerna + 45 ml of microlipid/can of 236 ml
 * re-evaluate GT feed in 2-3 weeks and adjust as required

Borderline hypoglycemia = BG between 3.1 -3.5 = Act and Be on Alert
 If awake and able to eat: give a snack containing glucose+ protein
 If asleep or unable to eat: give 15 g fast acting carbohydrate = Dex4gel 38g via GT
 Recheck BG in 15 minutes
 Repeat intervention as needed
 If Borderline hypoglycemia persists > 2 episodes, encourage meal

If Lethargic, Shaky OR BG 3.1-3.5 persists > 4 episodes,
Start continuous GT feeds DAYTIME and NIGHT; may eat in addition if she wishes to
 Run Glucerna + microlipid 45 ml/236 ml can of formula at 35 ml/hr via GT continuously 24/7
 Closely monitor BG
 Call CCS (encourage prompt clinic visit to evaluate for possible trigger)

Hypoglycemia = BG 3.0 or lower = Act IMMEDIATELY
 If awake and able to eat: give 15 g fast acting carbohydrate = Dex4gel 38g and then give a snack containing glucose+ protein
 If asleep or unable to eat: give 15 g fast acting carbohydrate = Dex4gel 38g via GT
 Recheck BG in 15 minutes
 Repeat intervention up to 2 times if required

If BG 3.0 or lower persists more than 2 times, then **Start continuous GT feeds;** may eat in addition if she wishes to
 Run Glucerna + microlipid 45 ml/236 ml can of formula at 35 ml/hr via GT continuously 24/7. Monitor BG closely (on continuous monitor); if BG stabilizes ≥ 3.5 then **continue GT feed** and Call CCS (encourage prompt clinic visit to evaluate for possible trigger)

Figure 1. Sample of care plan, see complete care plan in appendix.

The unique blend of acute and chronic care services has been a key factor in the long term sustainability of the program; meeting important needs of the families, the CCS healthcare team and the broader hospital services. For the children and families, they have the benefits and security of longitudinal care by a team that knows their child and family well and with whom a trusting relationship exists. They highly value avoiding the emergency department (ED) for the majority of acute care. Periodic

family satisfaction surveys indicate that we are meeting our care goals and parental expectations (see PROGRAM OUTCOMES below).

For the CCS healthcare team, delivery of acute care services balances the time and psychological investment of chronic care management, continually broadening our skill set and offering a rich learning environment. To be frank, we enjoy the fast paced environment of acute care and the immediately tangible rewards of acute interventions. This 'adrenaline' sustains the team as we deal with the much more complicated chronic issues that are sometimes unsolvable. As a result, we have remarkable staff retention, allowing for expertise through experience.

The broader hospital services, including subspecialists and acute care teams, value our contributions and the subsequent facilitation or reduction in the care that they provide. Over the years, we have built solid relationships with key subspecialty providers, especially in Neurology, Respiriology, Gastroenterology, Intensive Care, and Interventional Radiology. The most tangible outcomes of this collaboration are the "one-site" combined visits in the CCS clinic area which are routine for most

children and the ease of communication between the CCS team and subspecialists.

EDUCATIONAL AND ADVOCACY: Beyond clinical care, the MCH CCS team has been involved in a variety of educational projects and advocacy aimed at improving the quality and quantity of care for CMC.

Our team has led the development of a national curriculum in complex care, intended for postgraduate trainees in pediatrics. In partnership with the Royal College of Physicians and Surgeons of Canada, our accreditation body in pediatrics, exit examinations now have increased content on the care of CMC, in keeping with the reality of consultant pediatric care in Canada.

We offer a clinical fellowship in Complex Care, training the next generation of 'builders' in this field. For more information on this competitive fellowship, please contact the corresponding author of this paper or visit the McGill fellowship website: <http://www.mcgill.ca/pgme/programs/fellows-hip-programs>.

In concert with families and community care providers, we have spent the last several years standardizing evidence-based and evidence-informed homecare practices for

the most common nursing interventions in CMC and have developed a website with detailed step by step instructions for caregivers (Figure 2). Website address: *complexcareathomeforchildren.com*. Topics covered include how to use medical technologies (Figure 3) and everyday care of medical technologies (Figure 4) to how to prepare children and families for a life with medical technologies (Figure 5).

Healthcare in Canada is managed at a provincial level and in our province of Quebec, our team has been active in advocacy for improved homecare supports and have successfully brokered meaningful policy change and funding for these children and their families.

FINANCIAL PLAN

Healthcare in Canada is publicly funded by province; the CCS is funded through the McGill University Health Centre by the Ministry of Health and Social Services in Quebec. The annual operating budget is approximately 1.5 million dollars Canadian and primarily covers the salaries of nurses, administrative personnel and allied health partners; some of whom have multiple roles in other hospital services also. A smaller proportion of funds is designated for equipment and homecare supplies not otherwise covered by the provincial healthcare plan or private insurance. Physicians work on a fee-for-service basis and are not salaried by the hospital.

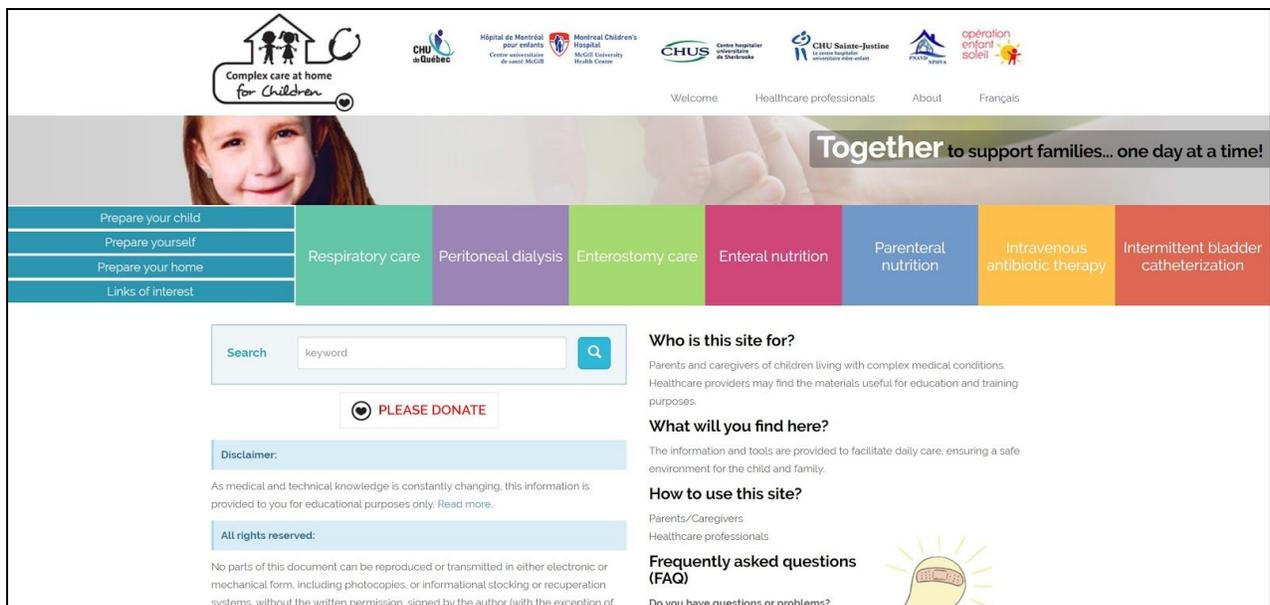


Figure 2. Home page of *Complex Care at Home for Children*.

Search

Aspiration of secretions

What is it?

How does it work?

Methods of care:

- Aspiration of oral secretions
- Nasopharyngeal aspiration of secretions
- Suctioning a tracheostomy tube

Learning objectives

Methods of care: summary

Everyday tips

FAQ

References

1 2 3 4 5 6 7 8 **9** 10 11 12 13 14 15

Step 8 Step 9 Step 10

Step 9: Insert the catheter

- Identify the maximal insertion length point on the catheter, using your previous measurements for the reference point.
- Ask your child to take slow deep breaths, if possible.
- Disconnect your child from the ventilator, if applicable.
- If there are many secretions visible in the tracheostomy cannula, block the suction valve** as you quickly but gently insert the catheter into the tracheostomy cannula, preferably when your child takes a breath in.
- If there are no visible secretions in the tracheostomy cannula,** then quickly but gently insert the catheter into the tracheostomy cannula, preferably when your child takes a breath in, **without blocking the suction valve.**
- Continue to insert the catheter to the reference point as previously determined; this number on the catheter should be aligned to the exterior rim entrance of the cannula connector.

Figure 3. Step 9 of “Suctioning a tracheostomy tube”

Parenteral nutrition

What is it?

How does it work?

Methods of care:

- Preparation of the parenteral nutrition solution and addition of additives
- Monitoring of the catheter site
- Catheter irrigation
- Administration of parenteral nutrition solution

Learning objectives

Methods of care: summary

Everyday tips

FAQ

References

Everyday tips

Search

Print all

Clothing Bathing and swimming Sleeping Nutrition and hydration Activities Travel and transportation Others

- Avoid getting the dressing wet because it may fall off. Bathing in shallow water is preferable to a shower.
- To protect the dressing from splashing, cover it with waterproof plastic wrap (eg, saran-wrap™) attached with tape so that the dressing stays dry.
- Never put the catheter or dressing in the bath water, even if it has been covered in plastic.
- Swimming is **not permitted** if your child has a peripherally inserted central catheter (“PICC line”), a central tunnel catheter (eg, Broviac®) or an implantable chamber catheter with the needle in place; otherwise, the dressing may become wet and peel off. If the catheter is not protected, it may come out or become infected.
- Your child can bathe and swim if he / she has an implantable chamber catheter (**Port-a-Cath®**) and the needle is not in place.

Figure 4. “Everyday tips: bathing and swimming” of Parenteral Nutrition section

Search

Prepare your child

Introduction

General suggestions

The pediatric approach

Distraction techniques

Positioning techniques

Therapeutic (medical) play

Encourage autonomy

Explain simply

Offering realistic choices

Common challenges with behaviour and suggested solutions

Recognize your child's strengths

Signs of stress in children

Suggestions for therapeutic (medical) play by developmental stage of the child

Infants Toddlers Preschoolers **School-aged children** Adolescents

Developmental stages and characteristic types of play

- Developing understanding and logic around their medical condition and required care.
- The play becomes more realistic and less dramatic.
- The child appreciates autonomy and is learning to adapt to the care needs.

Suggestions for medical play

- Medical play can be more structured, following the four phases **pediatric approach** (Anticipation, Preparation, Procedure and Recovery).
- In a progressive, age-appropriate way, your child can explore **reasonable choices** and try out different forms of distraction or positioning.
- You can ask your child more directly about what he/she feels and understands.
- The play itself may become more precise, mimicking the true treatment. This is an ideal way to explore how and when your child may wish to be more involved in the treatment delivery; this encourages autonomy and transition into the next phase of their development.
- Provide explanations according to age and level of development.

Figure 5. “Suggestions for therapeutic (medical) play by developmental stage: school-aged children”

The CCS has built an important relationship with the hospital Foundation and has been grateful to receive private donations through a variety of fundraisers; these resources have been invaluable in facilitating care.

PROGRAM OUTCOMES

Along with basic demographic statistics (enrollments, discharges, deaths and transfers), the CCS also tracks: acute care visits, hospital admissions, referrals to the Emergency Department, home/community visits and the use of the after hours telephone service. These results are not being published in this report.

Family satisfaction surveys are undertaken every few years; the last one collected in spring of 2018 focused on “medical home” quality indicators. We used the "Measure of Processes of Care", a self-report measure of parent's perceptions of the care they and their child received (assessment of family-centred behaviors of the healthcare team) in 5 domains.¹ We collected 29 surveys during the most recent survey

period. While we are not publishing the results of that survey in this report, the results showed that we could improve in two of the domains: ‘providing specific information about the child’ and ‘providing general information’. Specifically, parents wanted more written take home materials. We are responding to this with a new project: care binders.

PROGRAM LIMITATIONS

Like most complex care services elsewhere, we are challenged with an ever increasing number of referrals and resource restriction. Transition to adult care remains a daunting task. The care of children with moderate complexity; that is, those ‘not sick enough’ for admission to the CCS, is problematic and insufficient. Research remains a priority but has minimal remuneration making it a costly necessity, both in terms of time and money. Nonetheless, we are known, nationally and internationally as a centre of innovation for CMC, with specific expertise in educational outreach.

DISCLOSURES/CONFLICTS OF INTEREST & FUNDING: The authors do not have any disclosures.

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TO CITE

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1. Woodside, J., Rosenbaum, P., King, S., & King, G. (1998). The Measure of Processes of Care for Service Providers (MPOC-SP). © *CanChild* Centre for Childhood Disability Research, McMaster University.

IMAGES AND TABLES

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Education Innovations	<ul style="list-style-type: none"> ● <i>Complexcareathomeforchildren.com</i> ● National curriculum for pediatric postgraduate trainees

Table 1. Snapshot of CCS at MCH

CCS Action Plan for Parents / Caregivers

Name: XXXX **DOB:** **Weight:** XX kg **Date:** June 12, 2019
Goals of Care: Minimize/eliminate hypoglycemia and borderline hypoglycemia
CCS Daytime: ### ##### **CCS ON CALL:** ### ##### and ask to speak with the on-call nurse for CCS
Alerts: PORT, possible underlying mitochondrial disorder

GREEN ZONE I AM WELL!
<p>XXXX is feeling well AND does not have a fever. She is eating normally. Her blood glucose (BG)s have been stable and above 3.5 for the majority of the day and night. Continuous blood glucose monitoring via sc monitor.</p> <p>Serum BG 3.5 or greater (less than 13) DAYTIME: Eats by mouth as per usual; Continuous blood glucose monitoring; under the surveillance of a mature adult knowledgeable in the identification and treatment of hypoglycemia. SLEEP: Continuous GT feed at 35 mls/hour = Glucerna + 45 mls of microlipid/can of 236 ml * re-evaluate GT feed in 2-3 weeks and adjust as required</p> <p>Borderline hypoglycemia = BG between 3.1 -3.5 = Act and Be on Alert If awake and able to eat: give a snack containing glucose+ protein If asleep or unable to eat: give 15 g fast acting carbohydrate = Dex4gel 38g via GT Recheck BG in 15 minutes Repeat intervention as needed If Borderline hypoglycemia persists > 2 episodes, encourage meal</p> <p>If Lethargic, Shaky OR BG 3.1-3.5 persists > 4 episodes, Start continuous GT feeds DAYTIME and NIGHT; may eat in addition if she wishes to Run Glucerna + microlipid 45 ml/236 ml can of formula at 35 mls/hour via GT continuously 24/7 Closely monitor BG Call CCS (encourage prompt clinic visit to evaluate for possible trigger)</p> <p>Hypoglycemia = BG 3.0 or lower = Act IMMEDIATELY If awake and able to eat: give 15 g fast acting carbohydrate = Dex4gel 38g and then give a snack containing glucose+ protein If asleep or unable to eat: give 15 g fast acting carbohydrate = Dex4gel 38g via GT Recheck BG in 15 minutes Repeat intervention up to 2 times if required</p> <p>If BG 3.0 or lower persists more than 2 times, then Start continuous GT feeds; may eat in addition if she wishes to Run Glucerna + microlipid 45 ml/236 ml can of formula at 35 mls/hour via GT continuously 24/7 Monitor BG closely (on continuous monitor); if BG stabilizes ≥ 3.5 then continue GT feed and Call CCS (encourage prompt clinic visit to evaluate for possible trigger)</p> <p>If BG 3.0 or lower persists more than 2 times while ALREADY ON continuous GT feeds (eg. nighttime) then ACCESS PORT and START IV D10W infusion at 60mls/hour and alert CCS team; recommend evaluation in clinic at next available time; consider D10TPN solution for next 5-7 days if intercurrent illness present.</p>

Figure 1. Page 1 of complete care plan

YELLOW ZONE I AM SICK – ACT EARLY!
<p>XXXX is feeling unwell, even if mild symptoms OR has ANY of the following features: Not eating regular food/meals by mouth Diarrhea Fever Signs of a viral illness (cough, congestion, fatigue, refusal to eat)</p> <p>Call CCS (available 24/7) to organize prompt clinic visit to evaluate for possible trigger) Start continuous GT feeds DAYTIME and NIGHT even if BG >3.5; may eat in addition if she wishes to Run Glucerna + micro lipid 45 ml/236 ml can of formula at 35 mls/hour via GT continuously 24/7 Closely monitor BG</p> <p>If BG 3.0 or lower while ALREADY ON continuous GT feeds (eg. nighttime) then Access PORT and start IV D10W at 60 ml/hour; monitor closely. Call CCS.</p> <p>If Lethargic, Shaky OR BG 3.1-3.5 persists > 2 episodes while ALREADY ON continuous GT feeds then Access PORT and start IV D10W at 60 ml/hour; monitor closely. Call CCS.</p> <p>* If BG < 3.1 while on D10W at 60 mls/hour then increase rate to 90mls/hour. Call CCS.</p>
RED ZONE I AM IN DANGER AND NEED HELP
<p>XXXX is having recurrent or resistant hypoglycemia OR XXXX is vomiting or otherwise unable to tolerate GT feeds OR XXXX is lethargic or unresponsive OR XXXX has severe abdominal pain</p> <p>Access PORT and start D10W at 90 mls/hr Hold feeds by mouth and by GT</p> <p>GO TO EMERGENCY ASAP; Call 911 if unresponsive Call CCS Show this plan to health care team</p>

Figure 1. Page 2 of complete care plan

EMERGENCY and INPATIENT CARE RECOMMENDATIONS

X year old girl XXkg with ketotic hypoglycemia NYD ? mitochondrial disease; GT, continuous SC glucose monitor
Known for recurrent hypoglycemia, muscle spasms, generalized weakness, intermittent urinary incontinence. Has a
PORT central line.

Start or continue D10W at 1.2X maintenance = 70 mls/hr ASAP

Provides 6 mg CHO/kg/min

****Monitor BG closely** Q 30 min or more often (do not rely on continuous blood glucose monitor)**

If $BG \leq 3.0$, give 30 ml of D50 via GT or 1-2 ml/kg IV of D50W

Do serum lytes, LFTs, gas, glucose and urinary ketones

Evaluate underlying trigger, concurrent stress (eg. infection)

Avoid PO and GT feeds while acutely ill as this may trigger severe abdominal pain

Continue IV D10W with in-hospital monitoring for hypoglycemia

If $BG \leq 3.0$ while on D10W infusion, then after treating hypoglycemia, change IV fluids to:

D10W at 35 mls/hour (3 mg CHO/kg.min) + Intralipid at 12 ml/hour (3 g/kg/day)

This will provide 2:1 ratio similar to ketogenic diet; may develop nausea and vomiting

If there are more than 3 episodes of $BG \leq 3.0$ while on D10W + Intralipid, then consult Endocrinology.

Preparation for discharge

If no $BG \leq 3.0$ for 24 hours, then start continuous GT Glucerna + microlipid 45 ml/236 ml can of formula at 35
mls/hour AND decrease IV rate to 75% of original rate for one hour, continuing to monitor BG.

If she remains normoglycemic, further decrease IV rate to 50% of original rate for one hour, continuing enteral feeds
and BG monitoring.

If she remains normoglycemic, further decrease IV rate of 25% of original rate for one hour, continuing enteral feeds
and BG monitoring.

If she remains normoglycemic, stop IV fluids, maintain IV access with saline lock, monitor closely for 2 hours.

If tolerating continuous GT feed and having no hypoglycemia, consider discharge home with follow up in CCS on the
next calendar day (by phone if on a holiday).

Aim to transition to Green zone plan after 1-2 days of normoglycemia (discuss with CCS team)

Figure 1. Page 3 of complete care plan

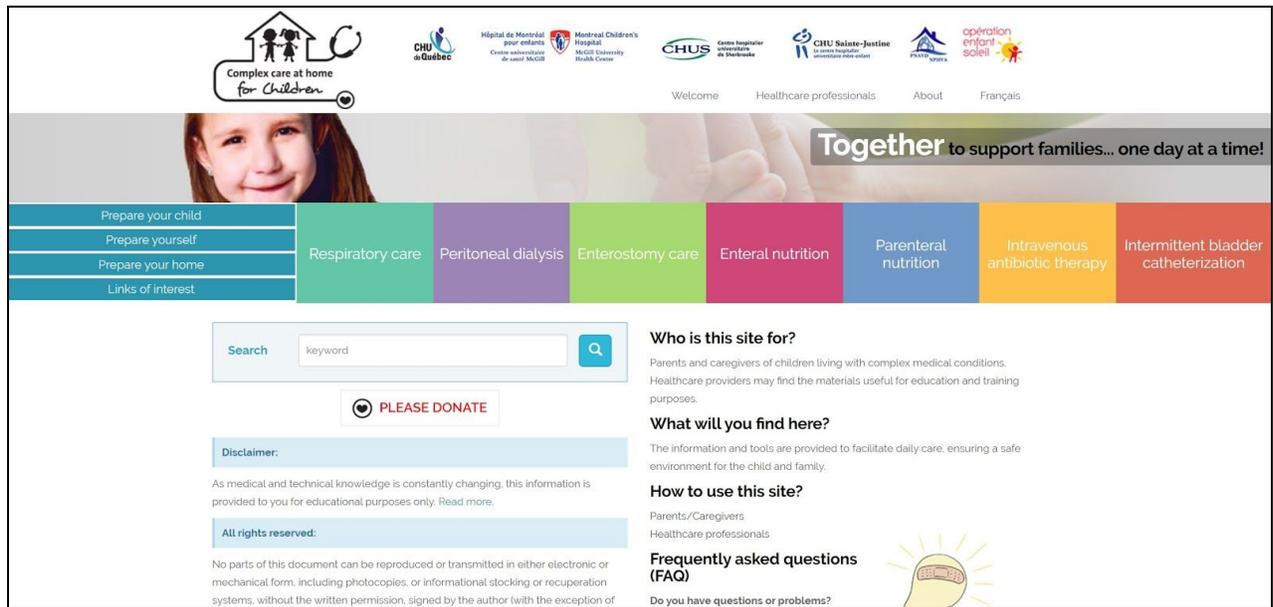


Figure 2. Home page of *Complex Care at Home for Children*.

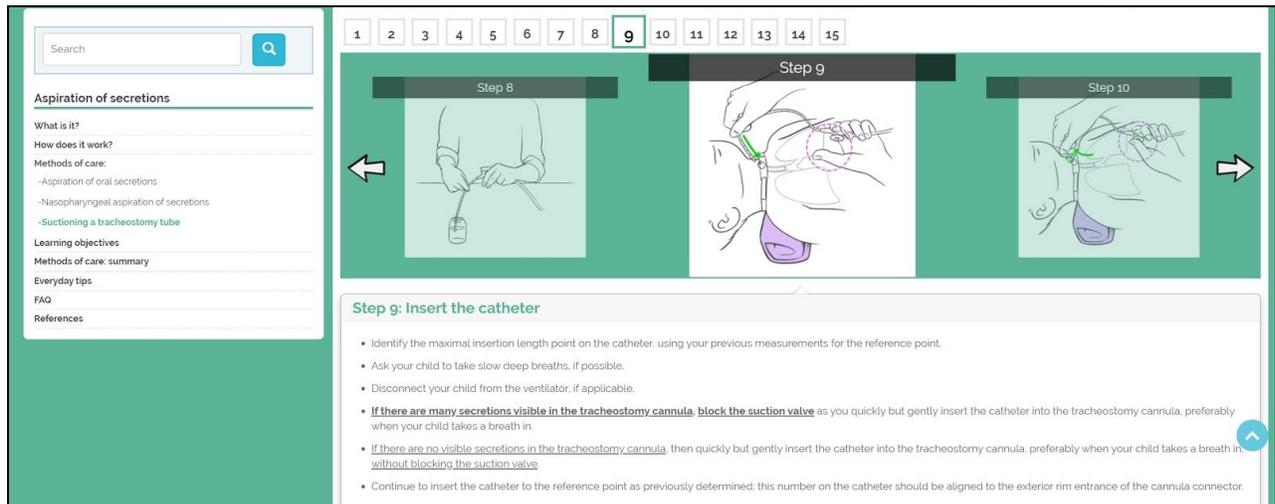


Figure 3. Step 9 of “Suctioning a tracheostomy tube”

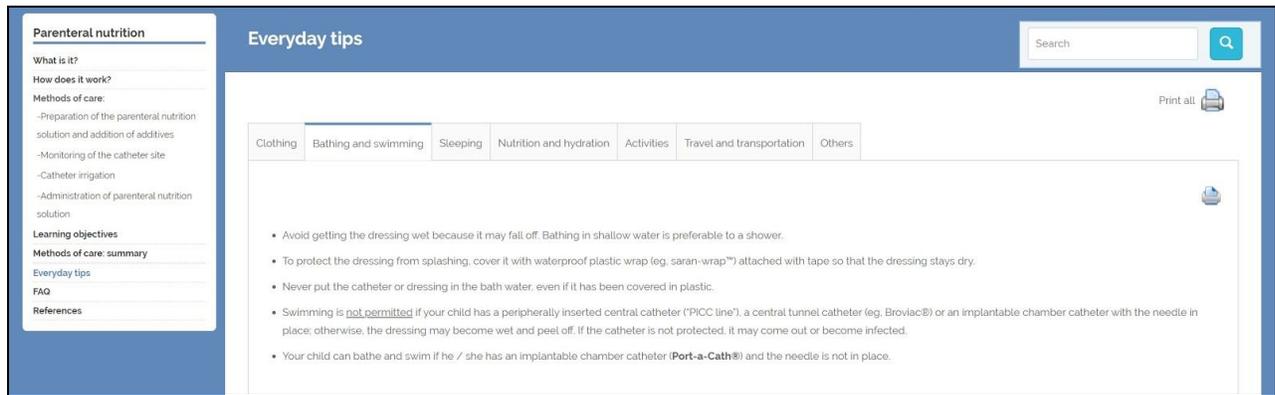


Figure 4. “Everyday tips: bathing and swimming” of Parenteral Nutrition section

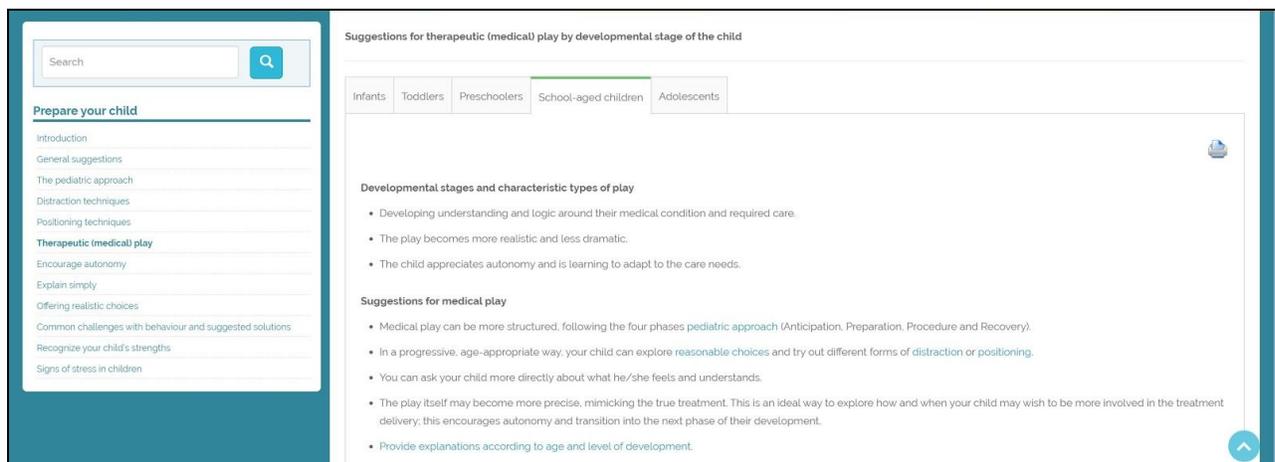


Figure 5. “Suggestions for therapeutic (medical) play by developmental stage: school-aged children”



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