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BACKGROUND

- Parents strongly desire to care for their child at home
- Most parents have no prior healthcare experience
- Meticulous, often complex, life-sustaining care required at home
- Plethora of care methods, many of which have little or no scientific support
- Small but important (stressful!) variations in care taught to parents

UNIQUE CONSIDERATIONS FOR CARE AT HOME COMPARED TO HOSPITAL BASED CARE

- Basic care steps are similar BUT
- Fewer caregivers to provide care in the home setting (pros & cons)
- Especially to help support the child (positioning, distraction)
- Especially to assist the main caregiver with the task at hand

PARENTAL FEEDBACK & PREFERENCES

- Simple clear care instructions
- Practical demonstrations supported with written resource materials
- Consistent information from different professionals involved in teaching homecare skills & knowledge
- Safe and effective homecare practices

- Parents and caregivers are often left confused and frustrated with differing recommendations for care
- Unnecessary variation increases the risk for error

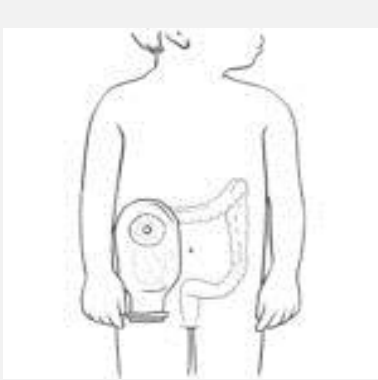
OBJECTIVE

- To standardize evidence-informed and sustainable home care practices for children with medical complexity

<https://complexcareathomeforchildren.com/>
<https://soinscomplexesadomicilepourenfants.com/>

WEBSITE FRAMEWORK

- **Prepare your child**, e.g., pediatric approach, positioning techniques; distraction techniques
- **Prepare yourself**, e.g., taking care of yourself, organizing your day
- **Prepare your environment** ,e.g., prevention of infection at home

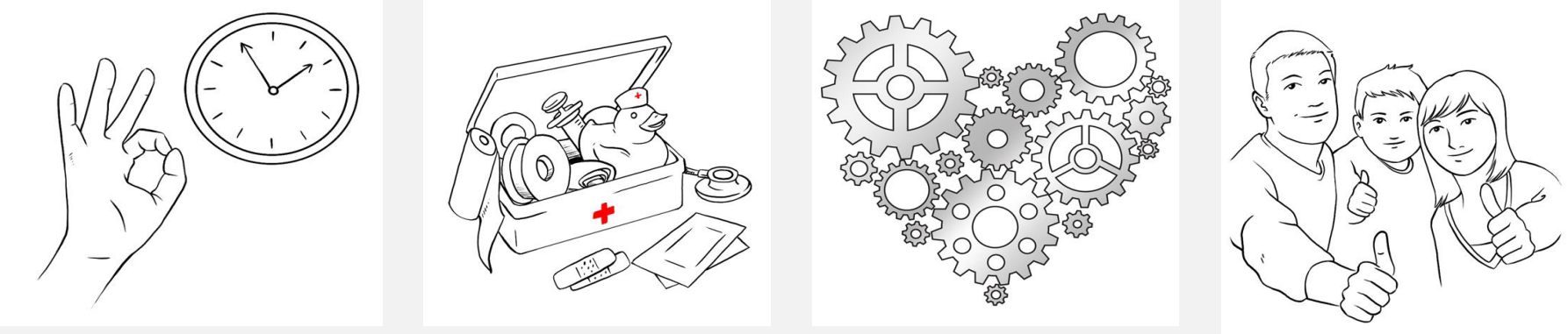
Care Modules:	Content	Example: How it works
Respiratory care	<ul style="list-style-type: none">• What is it• How does it work• Learning Objectives• Care Methods• Everyday Tips• Frequently Asked Questions	<div>An enterostomy allows gas and stools (poop) to pass directly from the intestine into a collection device (called an ostomy appliance or ostomy pouching system) that your child wears on the abdomen.</div> <div></div> <div>The ostomy appliance has two specific roles: it collects the stools, it protects the stoma and the skin around the stoma.</div>
Peritoneal dialysis		
Enterostomy care		
Enteral nutrition		
Parenteral nutrition		
Intravenous antibiotic therapy		
Intermittent bladder catheterization		

Additional Resources

- For healthcare professionals, e.g., hospital discharge of a child with medical complexity

Unique Features

- Pediatric Approach: Anticipation, Preparation, Procedure, Recuperation
- Medical Illustrations
- Teaching checklist
- Printable



PARTNERS

- CHU de Quebec, Université Laval
- CHU Sainte-Justine, Centre hospitalier universitaire mère-enfant
- CHUS, Centre hospitalier universitaire de Sherbrooke
- Montreal Children’s Hospital, McGill University Health Center
- Opération enfant-soleil
- Programme national d’assistance ventilatoire à domicile
- Centre intégré universitaire de santé et de services sociaux du Centre-Ouest-de -l’île- de -Montréal
- Centre d’expertise en santé de Sherbrook (CESS)

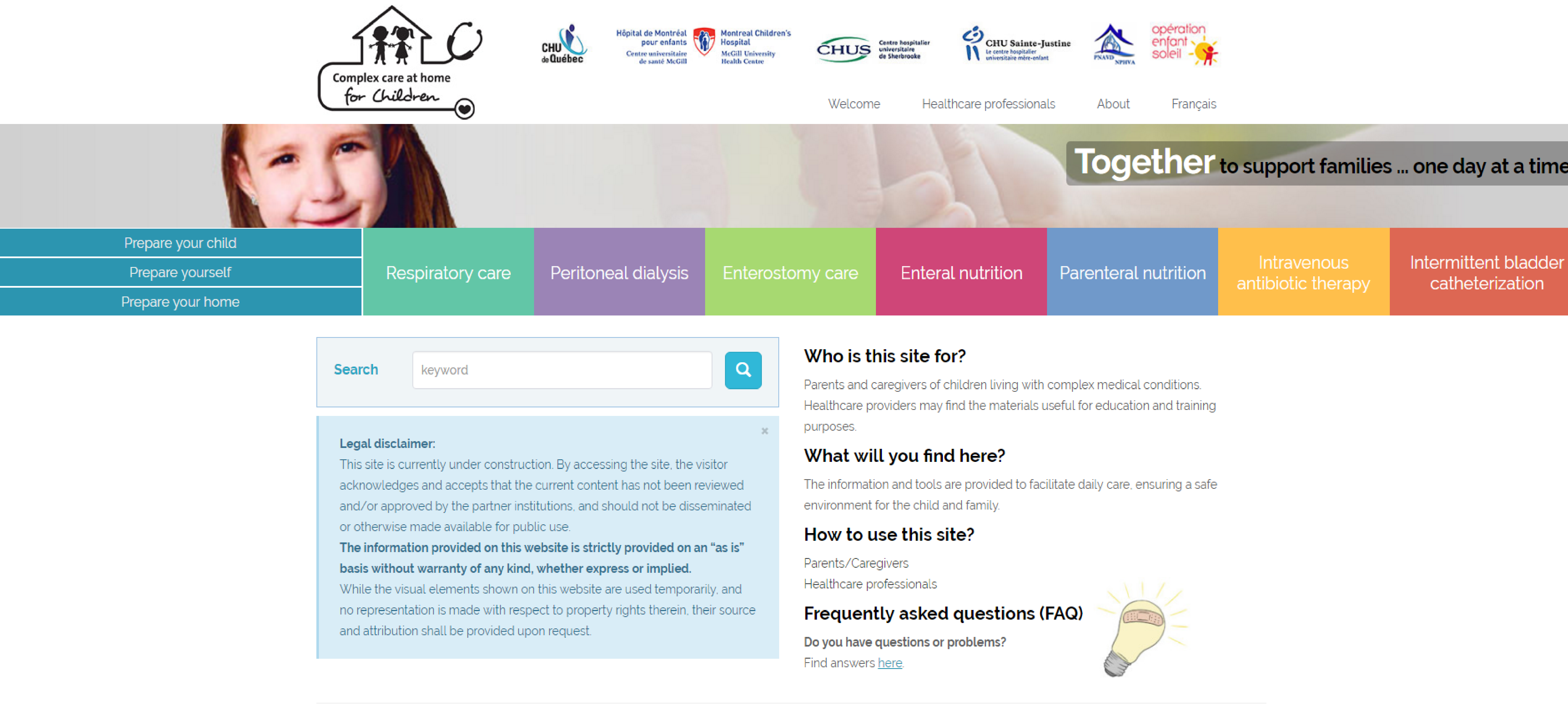
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METHODS

- Collection of existing care practices
- Comparison of practices with identification of discrepancies in recommendations
- Review of evidence to resolve discrepancies; consensus meeting to discuss and determine final recommendations
- Parental input on web format and additional topics of interest
- Drafted care practices and illustrations; further revisions and then final validation by partners
- Translation
- Utilization and impact to be measured
- Website maintenance

RESULT

- Web-based educational tool “Complex Care At Home For Children” that is accessible and practical



Family stories

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