

## **Pediatric Resources for Home Health Professionals in Nova Scotia**



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### Disclaimer

The following resources are designed to support current practices for home care in Nova Scotia, and are designed to provide general guidance and information about pediatric and family-centered care in the home. Should there be discrepancies, home care professionals should defer to their professional practice guidelines and organizational policies or procedures, and/or discuss questions with their manager.

This resource was developed with the understanding that home care professionals have received initial and ongoing training in patient and family assessment and communication. This resource is not a substitute for basic education in these domains.

### Instructions

Use the table of contents to find the subject area you're interested in.

Each subject area has its own table of resources, including information about specific subjects and time requirements for each resource to help you find what would be most helpful, whether you have a shorter or longer amount of time for education.

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## Pediatric Resources for Home Health Professionals in Nova Scotia

### Pediatric Communication Basics: Building Rapport and Explaining Health Information

These resources will help you learn developmentally-appropriate communication for getting to know children and youth in a beginning therapeutic relationship. They will also help you learn to communicate in an age-appropriate way when you're talking about health information.

Resource Title	Description	How To Access	Best Uses
Age-Appropriate Communication and Developmental Issues	Comprehension levels, communication strategies, and other tips for communication with children at each developmental stage.	Texas Children's Hospital Website: <a href="https://media.bcm.edu/documents/2015/76/palazzi-et-al-tch-guide-to-patient-communication.pdf">https://media.bcm.edu/documents/2015/76/palazzi-et-al-tch-guide-to-patient-communication.pdf</a>	In-depth learning, > 30 minutes.
Building Rapport with Children & Youth	Short (2 page) document with quick tips for communicating with pediatric patients.	Available from the IWK Health Centre: <a href="http://www.iwk.nshealth.ca/page/pediatric-resources-home-health-professionals">http://www.iwk.nshealth.ca/page/pediatric-resources-home-health-professionals</a>	Quick learning, < 5 minutes.
Practicing Building Rapport with Children & Youth	Several scenarios and pictures you can use to practice building rapport with children and youth.	Available from the IWK Health Centre: <a href="http://www.iwk.nshealth.ca/page/pediatric-resources-home-health-professionals">http://www.iwk.nshealth.ca/page/pediatric-resources-home-health-professionals</a>	Quick or in-depth learning – you choose how many scenarios.
Communicating with Children in Healthcare	A video (2 minutes) outlining basic strategies on how to communicate and build rapport with children and families in health care situations.	Available from AUS Med: <a href="https://www.youtube.com/watch?v=tOZDAVj3X5Y">https://www.youtube.com/watch?v=tOZDAVj3X5Y</a>	Quick learning, 2 minutes.
Talking to your Pediatric Patients	A short website article with tips from a pediatrician.	Available from UCLA Medical School: <a href="https://medschool.ucla.edu/body.cfm?id=1158&amp;action=detail&amp;ref=806">https://medschool.ucla.edu/body.cfm?id=1158&amp;action=detail&amp;ref=806</a>	Quick learning, < 5 minutes.
Communicating with Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information	A detailed article on the basics of communicating with pediatric patients and families, as well as information on more complex communication.	Available online from the American Academy of Pediatrics: <a href="https://pediatrics.aappublications.org/content/pediatrics/121/5/e1441.full.pdf">https://pediatrics.aappublications.org/content/pediatrics/121/5/e1441.full.pdf</a>	In-depth learning, > 30 minutes.

5 Tips on Connecting with Your Pediatric Patients	Short blog with 5 tips useful for any clinicians working with children.	Available online from CHOC Docs Blog: <a href="https://docs.chocchildrens.org/5-tips-connecting-pediatric-patients/?_hstc=45511931.a1d2850e30e07de78b44b1421d65dad6.1569105712267.1569105712267.1&amp;_hssc=45511931.4.1571079881497&amp;_hsfp=3570664279&amp;_ga=2.260191693.1319690361.1571079899-963079020.1569105724">https://docs.chocchildrens.org/5-tips-connecting-pediatric-patients/?_hstc=45511931.a1d2850e30e07de78b44b1421d65dad6.1569105712267.1569105712267.1&amp;_hssc=45511931.4.1571079881497&amp;_hsfp=3570664279&amp;_ga=2.260191693.1319690361.1571079899-963079020.1569105724</a>	Quick reference, 5 minutes.
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## Pediatric Communication: Patients with Neuro-Developmental Challenges

The following resources provide guidance for communicating and interacting with children and youth who have minimal verbal communication abilities.

Resource Title	Description	How To Access	Best Uses
Communicating with Children and Youth with Neuro-Developmental Delay	A quick reference guide (2 pages) that provides tips for clinicians working with this specialty population.	Available from the IWK Health Centre: <a href="http://www.iwk.nshealth.ca/page/pediatric-resources-home-health-professionals">http://www.iwk.nshealth.ca/page/pediatric-resources-home-health-professionals</a>	Quick reference, 5-10 minutes.
11 Ways to Communicate with Children with Special Needs	A website with quick and easy-to-understand ideas.	Available from Unity Point at Home: <a href="https://www.unitypoint.org/homecare/article.aspx?id=538d6c28-b8c1-488e-bdc9-6ff5900ccfff">https://www.unitypoint.org/homecare/article.aspx?id=538d6c28-b8c1-488e-bdc9-6ff5900ccfff</a>	Quick reference, 5-10 minutes.

## Procedures and Distraction in Pediatrics

This section of resources is designed to support health professionals who need to do procedures with children and youth in the home. Some resources are for specific procedures such as needle-related procedures, some are general tips around any type of procedure, and others are focused on how to effectively distract children and youth during procedures. Several resources will help you know how to guide parents and caregivers and elicit their help during procedures.

Resource Title	Description	How To Access	Best Uses
Tips for Procedures in Children and Youth	Quick reference tips. Includes a care plan template for doing	Available from the IWK Health Centre: <a href="http://www.iwk.nshealth.ca/page/pediatric-">http://www.iwk.nshealth.ca/page/pediatric-</a>	Quick learning, 5 minutes.

	procedures with a particular patient.	<a href="#">resources-home-health-professionals</a>	Care plan template for procedures.
Needle Pain Prevention in Pediatrics	A webinar (35 minutes) outlining why preventing needle pain in kids is important, and the 4 steps of needle pain prevention.	Available from Children's Healthcare Canada: <a href="https://youtu.be/uSdHlvv_uEPo">https://youtu.be/uSdHlvv_uEPo</a>	In-depth learning ~ 30 minutes. Principles are suitable for many painful procedures.
The Power of a Parent's Touch	A video (2.5 minutes) outlining why preventing pain in infants is important, and how to use skin-to-skin care and breastfeeding to minimize pain during procedures.	Available from the IWK Health Centre: <a href="https://www.youtube.com/watch?v=3nqN9c3FWn8&amp;feature=youtu.be">https://www.youtube.com/watch?v=3nqN9c3FWn8&amp;feature=youtu.be</a>	Quick learning, < 3 minutes.
It Doesn't Have to Hurt	A video (2 minutes) outlining steps that can be taken to prevent pain during children's procedures.	Available from the IWK Health Centre: <a href="https://youtu.be/KgBwVS_Yqfps">https://youtu.be/KgBwVS_Yqfps</a>	Quick learning, 2 minutes.
Distraction Toolkit	A variety of resources for clinicians to learn about distracting kids during procedures.	Available from Children's Healthcare Canada: <a href="https://ken.childrenshealthcarecanada.ca/xwiki/bin/view/Paediatric+Pain/Distraction+Toolkit">https://ken.childrenshealthcarecanada.ca/xwiki/bin/view/Paediatric+Pain/Distraction+Toolkit</a>  Quick references include "positions for comfort" and a "tip sheet" for clinicians, as well as power point slides, videos, and research articles to learn more about distraction for kids.	Quick reference and in-depth learning options.
Helping Your Child During Medical Procedures	A video (3 minutes) that a clinician and family could watch together, to give families ideas how to help and distract their child during a procedure.	Available from the University of Illinois Children's Hospital: <a href="https://www.youtube.com/watch?v=D6GSPUVh2k0&amp;feature=youtu.be">https://www.youtube.com/watch?v=D6GSPUVh2k0&amp;feature=youtu.be</a>	Quick learning, 3 minutes.
Reducing Your Child's Discomfort During Procedures	A websites designed for parents, but also helpful for clinicians, to plan how to help children during procedures. A	Available from the Royal Children's Hospital Melbourne: <a href="https://www.rch.org.au/kidsinfo/fact_sheets/Reduc">https://www.rch.org.au/kidsinfo/fact_sheets/Reduc</a>	Could be used for quick learning, 5-10 minutes, or in-depth learning > 20 minutes if you

	clinician and family could use this resource together.	<a href="#">e childrens discomfort during tests and procedure s/</a>	explore the entire site.
Ways You Can Help Children Cope During Treatments and Procedures	Quick 1-page guide for parents and clinicians.	Available from BC Children's Hospital: <a href="http://www.bcchildrens.ca/Child-Life-site/Documents/Tips%20for%20Caregivers.pdf">http://www.bcchildrens.ca/Child-Life-site/Documents/Tips%20for%20Caregivers.pdf</a>	Quick reference, < 5 minutes.
Dressing Changes	Although designed for in-hospital dressing changes, this document has some ideas for how clinicians can explain dressing changes in a way younger children can understand.	Available from BC Children's Hospital: <a href="http://www.bcchildrens.ca/Child-Life-site/Documents/Dressing%20Change%20Prep%20Book%202018.pdf">http://www.bcchildrens.ca/Child-Life-site/Documents/Dressing%20Change%20Prep%20Book%202018.pdf</a>	Quick reference, 5 minutes.
Open Pediatrics: Non-Pharmacologic Pain Management Videos	A series of videos about non-pharmacologic pain management, by different age groups.	Video series available at: <a href="https://www.openpediatrics.org/assets/video/non-pharmacologic-pain-management-strategies">https://www.openpediatrics.org/assets/video/non-pharmacologic-pain-management-strategies</a>  Look for the drop-down menu next to "Chapter 1" to find the videos:  Intro (1.5 minutes) Age-Appropriate Coping Strategies (0.5 minute) Infants (1 minute) Toddlers (1 minute) Preschoolers (1 minute) Schoolchildren (1 minute) Adolescents (0.5 minute)	Quick reference learning (videos 0.5-1.5 minutes)  Open Pediatrics videos can be downloaded.

## Pediatric Palliative Care and End-Of-Life Care

These resources will help you understand the differences between adult and pediatric palliative care as you care for patients receiving longer-term pediatric palliative care. A number of resources also focus on the challenges of pediatric end-of-life care, including self-care for clinicians. There is also information on anticipatory grief and grief support for families.

Resource Title	Description	How To Access	Best Uses
Top Ten Tips Palliative Care Clinicians Should Know About	Short and practical research article (5 pages) with quick tips on	Look up in an online library or database using DOI 10.1089/jpm.2018.0482 – or the full	Allow 10 minutes for a quick read, or in-depth learning of >



Caring for Children	the differences for pediatric palliative care.	citation is in the reference list under first author Jordan.	30 minutes to take time to reflect.
Early Integration of Pediatric Palliative Care: For Some Children, Palliative Care Starts at Diagnosis	Short and practical research article (4 pages) introducing pediatric palliative care as more than just end-of-life care.	Look up in an online library or database using DOI 10.1097/01.mop.0000193266.86129.47 – or the full citation is in the reference list under first author Mack.	Moderate time of 10-15 minutes to read, or in-depth learning of > 30 minutes to take time to reflect.
Age Appropriate Communication and Developmental Issues - Talking About Death: A Special Situation	A table showing how the ages or developmental stages of children understand death.	Available on the Texas Children's Hospital Website:  See pp. 32-33: <a href="https://media.bcm.edu/documents/2015/76/palazzi-et-al-tch-guide-to-patient-communication.pdf">https://media.bcm.edu/documents/2015/76/palazzi-et-al-tch-guide-to-patient-communication.pdf</a>	Quick reference of 5 minutes, or can be used to guide in-depth learning.
Pediatric Palliative Care Podcasts	A series of podcasts on topics related to pediatric palliative care.	Available from the Canadian Pediatric Society: <a href="https://www.pedscases.com/specialty-area/palliative-care">https://www.pedscases.com/specialty-area/palliative-care</a>  Guiding principles of pediatric palliative care (~ 15 minutes).  Medical assistance in dying in children (~22 minutes).  Pain assessment in verbal and non-verbal children (~ 15 minutes).	In-depth learning, ~15-25 minutes.
Open Pediatrics: Pediatric Palliative Care Video Series	A series of videos on pediatric palliative and end-of-life care.	Videos available at: <a href="https://www.openpediatrics.org/assets/video/palliative-and-end-life-care">https://www.openpediatrics.org/assets/video/palliative-and-end-life-care</a>  Look for the drop-down menu next to "Chapter 1" to find the videos: Overview of Palliative Care (8 minutes) Patient Eligibility (5.5 minutes) Understanding Suffering (9.5 minutes) Palliative Care Outcomes (4.5 minutes)	Quick-reference and in-depth learning options (videos of 5-10 minutes each).  Open Pediatrics videos can be downloaded.

Orphanet	A searchable website for rare diseases and medications.	<a href="https://www.orpha.net/consor/cgi-bin/index.php">https://www.orpha.net/consor/cgi-bin/index.php</a>	Quick or in-depth learning options.
About Kids Health: Preparing for the Death of a Child	A short but detailed article meant for families, but also helpful for health professionals, describing how to prepare for the death of a child.	Available from About Kids Health: <a href="https://www.aboutkidshealth.ca/Article?contentid=1689&amp;language=English">https://www.aboutkidshealth.ca/Article?contentid=1689&amp;language=English</a>	Quick learning, 5-10 minutes.
Introduction to Pediatric Palliative Care	A 1-hour webinar about pediatric palliative care, including how it's different from adult palliative care.	Available from the Children's Hospital of Philadelphia: <a href="https://media.chop.edu/data/files/chop-open-presentations/palliative-care/03/index.html">https://media.chop.edu/data/files/chop-open-presentations/palliative-care/03/index.html</a>	In-depth learning (1 hour).
Case Study in Pediatric Palliative Care	A 1-hour webinar exploring the journey of Philip and his family over 3 years receiving palliative care.	Available from the Children's Hospital of Philadelphia: <a href="https://media.chop.edu/data/files/chop-open-presentations/palliative-care/14/index.html">https://media.chop.edu/data/files/chop-open-presentations/palliative-care/14/index.html</a>	In-depth learning (1 hour).
Caring for the Dying Child	A 1-hour webinar exploring this challenging topic.	Available from the Children's Hospital of Philadelphia: <a href="https://media.chop.edu/data/files/chop-open-presentations/palliative-care/18/index.html">https://media.chop.edu/data/files/chop-open-presentations/palliative-care/18/index.html</a>  This is hospital-focused but still has information that is helpful for the home setting.	In-depth learning (1 hour).
Striving and Thriving in Pediatric Palliative Care	A 1-hour webinar on self-care in pediatric palliative and end-of-life care situations.	Available from the Children's Hospital of Philadelphia: <a href="https://media.chop.edu/data/files/chop-open-presentations/palliative-care/22/index.html">https://media.chop.edu/data/files/chop-open-presentations/palliative-care/22/index.html</a>	In-depth learning (1 hour).
Courageous Parents Network	A website developed by parents of seriously ill children, with oversight from	<a href="https://courageousparentsnetwork.org/">https://courageousparentsnetwork.org/</a>  Helpful content for health professionals on grief, anticipatory grief, supporting	Quick or in-depth learning options such as stories, podcasts, and quick reference documents.

	health professionals.	parents and siblings as a child approaches end-of-life, and more.	Subscribe to the provider portal for access to more resources.
Kids Grief	A website aimed at helping parents and other adults talk to kids and teens about death and dying, supported by health professionals.	<a href="https://kidsgrief.ca/">https://kidsgrief.ca/</a> There are brief kids grief articles in the resources section (top right of home page) and a series of short articles in the “Talking about Death and Dying” module (bottom of home page).	Predominantly quick learning options (< 5 minutes) such as articles and module sub-topics. If you read an entire module, it will take longer, such as 30-60 minutes.

### Children and Youth with Medical Complexity

A child or youth with medical complexity (CYMC) has one or more health conditions that affect multiple body systems; has functional limitations that often include technological dependence; has high service use across health and other sectors; and their family has high self-identified needs.

This section of resources will help you learn about the unique day-to-day challenges faced by these patients and families as they live in their homes and communities, and how to provide care that will address their multiple, complex needs. There is also information about technological devices (e.g. feeding tubes, tracheostomies, ventilators) and searchable websites that include information on rare health conditions, medications, and more.

Resource Title	Description	How To Access	Best Uses
Nurse-Parent Dialogue: Illuminating the Evolving Pattern of Families with Children who are Medically Fragile	Moderate length research article (8 pages) that describes the experience of families with children who are medically fragile – the themes are how families are “living in uncertainty” and “experiencing order in chaos”.	Look up in an online library or database using DOI 10.1177/0894318403253130 – or the full citation is in the reference list under author Tommet.	In-depth learning and reflection, > 30 minutes.
Home Care of Children and Youth with Complex Health Care Needs and Technology Dependencies	Detailed research article (8 pages) that outlines the care of this specialty population, including a section on home care (pp. 1000-1001) and family needs (pp. 1002-1003).	Look up in an online library or database using DOI 10.1542/peds.2012-0606 – or the full citation is in the reference list under first author Elias.	In-depth learning and reflection, > 30 minutes.

Bright Futures: Promoting Health for Children and Youth with Special Health Care Needs	Quick reference on the care of this specialty population by age group, including assessment, developmental stages, family needs, and more.	Available online from the American Academy of Pediatrics: <a href="https://brightfutures.aap.org/Bright%20Futures%20Documents/BF4_CYSHCNHealth.pdf">https://brightfutures.aap.org/Bright%20Futures%20Documents/BF4_CYSHCNHealth.pdf</a>  Birth to 11 months, pp. 70-72. 1 to 4 years, pp. 72-73. 5 to 10 years, pp. 73-74. 11 to 21 years, pp. 74-75.	Quick reference of 5 minutes for each age group.
Guideline for the Management of Medically Complex Children and Youth Through the Continuum of Care	Canadian national guideline on the care of children and youth with medical complexity. Can be used as a comprehensive guide, or use individual sections as a quick reference.	Available online from Children's Healthcare Canada: <a href="https://ken.childrenshealthcarecanada.ca/xwiki/bin/download/Management+of+Medically+Complex+Children+and+Youth+Across+the+Continuum+of+Care/WebHome/CAPHC%20National%20Complex%20Care%20Guideline%202018_final.pdf">https://ken.childrenshealthcarecanada.ca/xwiki/bin/download/Management+of+Medically+Complex+Children+and+Youth+Across+the+Continuum+of+Care/WebHome/CAPHC%20National%20Complex%20Care%20Guideline%202018_final.pdf</a>  See p. 17: How to identify a child or youth with medical complexity. See p. 26: What to include in a care plan for a child or youth with medical complexity.	Quick reference for individual sections, in-depth learning > 30 minutes for the entire guideline.
The Chronic Pain Assessment Toolbox for Children with Disabilities	Webinar (25 minutes) explaining how experts developed a tool to assess chronic pain in children with disabilities – includes links to a clinical toolbox.	Available from Children's Healthcare Canada: <a href="https://www.youtube.com/watch?v=HDGXmsDn25k&amp;feature=youtu.be">https://www.youtube.com/watch?v=HDGXmsDn25k&amp;feature=youtu.be</a>  Toolbox for pain assessment: <a href="http://www.hollandbloorview.ca/research-education/knowledge-translation-products/chronic-pain-assessment-toolbox-children">http://www.hollandbloorview.ca/research-education/knowledge-translation-products/chronic-pain-assessment-toolbox-children</a>	In-depth learning ~ 30 minutes.
Fact Sheet: Medically Complex Children	A 1-page sheet describing and defining children and youth with medical complexity.	Available from Children's Healthcare Canada: <a href="https://images.squarespace-cdn.com/content/v1/5bd8a55e4eddec150a2acdb/1544463180836-VT72S3T72SC2CNRCVLMH/ke">https://images.squarespace-cdn.com/content/v1/5bd8a55e4eddec150a2acdb/1544463180836-VT72S3T72SC2CNRCVLMH/ke</a>	Quick learning, 5 minutes.

		<p><a href="https://www.youtube.com/watch?v=17ZwdGBToddI8pDm48kJZW6zhob9awPz640NRRJcR7gQa3H78H3Y0txjaivOfDoOvxcdMmMKkDsyUqMSsMWxHk725yiiHCCLfrh8O1z4YTzHvnKhyp6Da-NYroOW3ZGj0BKy3azqku80C789I0pa5utEcoDWpn0hH27EPHs6YpqR16Q5b3RWnth7I4iloUNq0q9F7nstxtmKTcbqtlw/MedicallyComplexChildrenPHactSheet.png">17ZwdGBToddI8pDm48kJZW6zhob9awPz640NRRJcR7gQa3H78H3Y0txjaivOfDoOvxcdMmMKkDsyUqMSsMWxHk725yiiHCCLfrh8O1z4YTzHvnKhyp6Da-NYroOW3ZGj0BKy3azqku80C789I0pa5utEcoDWpn0hH27EPHs6YpqR16Q5b3RWnth7I4iloUNq0q9F7nstxtmKTcbqtlw/MedicallyComplexChildrenPHactSheet.png</a></p>	
Global Developmental Delay and Intellectual Disability	This webinar (18 minutes) is designed for pediatricians but contains basic information for any clinicians. It's about caring for children and youth with medical complexity who also have global developmental delay or intellectual disability.	<p>Available from the Canadian Pediatric Society:  <a href="http://pedscases.com/global-developmental-delay-intellectual-disability-cps-podcast">http://pedscases.com/global-developmental-delay-intellectual-disability-cps-podcast</a></p> <p>Note that not all children and youth with medical complexity have global developmental delay or intellectual disability.</p>	In-depth learning, ~ 20 minutes.
If You Only Knew... The Voices of Families of Children with Complex Care Needs	Series of 8 videos exploring the experiences and perspectives of families of this special population (videos are 5 to 8 minutes each).	<p>Available from Children's Healthcare Canada and In-Gauge:  <a href="https://www.youtube.com/watch?v=ghsKm1Zm6ro&amp;list=PLdQfM1_yW0Pt13s0syOZGBvuUyXUZ1bHG">https://www.youtube.com/watch?v=ghsKm1Zm6ro&amp;list=PLdQfM1_yW0Pt13s0syOZGBvuUyXUZ1bHG</a></p>	Quick reference or in-depth learning options.
Complex Care at Home for Children	Developed by pediatric experts in Quebec, this website has information specifically about home care for children and youth with medical complexity. It's aimed at families but is also suitable for health professionals.	<p>Available at:  <a href="https://complexcareathomeforchildren.com/">https://complexcareathomeforchildren.com/</a></p> <p>Topic highlights: Preparing the child for home care, families preparing themselves for home care, preparing the home itself, tracheostomies, ventilators, cough assist machines, ostomy care, catheterization, and more.</p>	Quick reference and in-depth learning options.
Open Pediatrics Resource Videos	From Boston Children's Hospital, there are a variety of information videos and webinars on topics that support the care of all	<p>All videos are listed at:  <a href="https://www.openpediatrics.org/resources/all?title=&amp;flagged=All&amp;field_asset_type_tid%5B%5D=511&amp;sort_bef_combine">https://www.openpediatrics.org/resources/all?title=&amp;flagged=All&amp;field_asset_type_tid%5B%5D=511&amp;sort_bef_combine</a></p>	Quick reference and in-depth learning topics.

	children, with many topics specifically for those with medical complexity.	<a href="#">=created+DESC&amp;items_per_page=20&amp;og_group_ref_tar</a>	Open Pediatrics videos can be downloaded.
Open Pediatrics: G-Tube Videos	Basic information on Gastrostomy or G-tubes and their care.	G-Tube Basics (1.5 minutes): <a href="https://www.openpediatrics.org/assets/video/gastrostomy-tube-basics">https://www.openpediatrics.org/assets/video/gastrostomy-tube-basics</a> G-Tube Balloon Assessment in the Home (2 minutes): <a href="https://www.openpediatrics.org/assets/video/assessment-gastrostomy-tube-balloon-home-setting">https://www.openpediatrics.org/assets/video/assessment-gastrostomy-tube-balloon-home-setting</a> Connecting and Disconnecting a G-Tube Extension Set (1 minute): <a href="https://www.openpediatrics.org/assets/video/connecting-and-disconnecting-g-tube-extension-set">https://www.openpediatrics.org/assets/video/connecting-and-disconnecting-g-tube-extension-set</a>	Quick learning, < 2 minutes for each video.  Open Pediatrics videos can be downloaded.
Open Pediatrics: Tracheostomy Videos	Short videos on tracheostomies and their care.	Look for the drop-down menu next to “Chapter 1”, “Part 1”, or “Case #1” to find the videos:  Basic tracheostomy information – 5 videos (2.5, 1, 1.5, 1.5, and 2 minutes): <a href="https://www.openpediatrics.org/assets/video/tracheostomy-primer">https://www.openpediatrics.org/assets/video/tracheostomy-primer</a> Tracheostomy care at home – 3 videos (3, 7, and 2.5 minutes): <a href="https://www.openpediatrics.org/assets/video/nicu-nursery---tracheostomy-care-home-setting">https://www.openpediatrics.org/assets/video/nicu-nursery---tracheostomy-care-home-setting</a> Tracheostomy troubleshooting – 4 videos (5, 3.5, 3.5, and 5.5 minutes): <a href="https://www.openpediatrics.org/assets/video/tracheostomy-troubleshooting?chapter=1">https://www.openpediatrics.org/assets/video/tracheostomy-troubleshooting?chapter=1</a>	Quick learning, 2-7 minutes for each video. Could also be used as part of in-depth learning.  Open Pediatrics videos can be downloaded.
Open Pediatrics: Respiratory Assessment Video	A short (4.5 minute) video describing how to recognize respiratory distress and failure in children.	Video available at: <a href="https://www.openpediatrics.org/assets/video/recognizing-respiratory-distress-and-failure">https://www.openpediatrics.org/assets/video/recognizing-respiratory-distress-and-failure</a>	Quick reference, < 5 minutes. Open Pediatrics videos can be downloaded.

Open Pediatrics: Ventilation Videos	<p>A series of videos about ventilation and home ventilation.</p> <p>Some ventilator videos are at a hospital level of detail but contain some information that would be useful to home health professionals.</p>	<p>Look for the drop-down menu next to “Chapter 1” to find the videos:</p> <p>Non-Invasive Positive Pressure Ventilation at Home (5.5 minutes – first video only):  <a href="https://www.openpediatrics.org/assets/video/managing-nippv-home-and-indications-return-hospital">https://www.openpediatrics.org/assets/video/managing-nippv-home-and-indications-return-hospital</a></p> <p>CPAP and BiPAP at Home (9.5 minutes):  <a href="https://www.openpediatrics.org/assets/video/how-navigate-cpap-and-bipap-home">https://www.openpediatrics.org/assets/video/how-navigate-cpap-and-bipap-home</a></p> <p>Ventilator Safety (1.5, 4, 2.5, 2, 1, and 7.5 minute videos):  <a href="https://www.openpediatrics.org/assets/video/ventilator-safety-assessment">https://www.openpediatrics.org/assets/video/ventilator-safety-assessment</a></p>	<p>Quick and in-depth learning options (videos of 2-10 minutes in length).</p> <p>Open Pediatrics videos can be downloaded.</p>
Open Pediatrics Videos: Home Visit for a Child with Medical Complexity	<p>A series of videos about Jack, a child with medical complexity, and his family, and how they live at home and in their community every day.</p>	<p>Video series:  <a href="https://www.openpediatrics.org/collection/virtual-home-visit-child-medical-complexity">https://www.openpediatrics.org/collection/virtual-home-visit-child-medical-complexity</a></p> <p>Key Topics:  Meet Jack (3 minutes)  Home Accessibility and Safety (8.5 minutes)  Medication Safety (6 minutes)  Travel Outside the Home (5 minutes)  Family and Community Participation (5.5 minutes)  Provider-Family Partnerships (7 minutes)</p>	<p>Quick or in-depth learning options (3-9 minutes per video).</p> <p>Open Pediatrics videos can be downloaded.</p>
Orphanet	<p>A searchable website for rare diseases and medications.</p>	<p><a href="https://www.orpha.net/consor/cgi-bin/index.php">https://www.orpha.net/consor/cgi-bin/index.php</a></p>	<p>Quick or in-depth learning options.</p>
About Kids Health	<p>Created by experts at Sick Kids Hospital in Toronto, this is a searchable site with information and videos on pediatric health information.</p>	<p><a href="https://www.aboutkidshealth.ca/">https://www.aboutkidshealth.ca/</a></p> <p>Topics to search for may include health conditions, medications, technology such as CPAP, G-tubes, and more.</p>	<p>Mostly quick learning, but in-depth options are available as well.</p>

Connected Care	A special learning hub within About Kids Health focused on complex care topics. Includes written information, pictures, and diagrams.	<a href="https://www.aboutkidshealth.ca/connectedcare">https://www.aboutkidshealth.ca/connectedcare</a> Helpful topics include G- and J-tubes, NG tubes, vascular access devices, tracheostomy care, and injections.	Quick learning and in-depth options are available.
Courageous Parents Network	A website developed by parents of seriously ill children, with oversight from health professionals.	<a href="http://courageousparentsnetwork.org">http://courageousparentsnetwork.org</a> Helpful content for health professionals on rare diseases, challenging symptoms such as neuropathic pain, supporting the entire family, patient and family stories, and more.	Quick or in-depth learning options such as stories, podcasts, and quick reference documents.

### Pediatric Family Assessment Resources

These two resources will help you incorporate the pediatric family-centered perspective into your initial and ongoing in-home assessments by providing conversational guides and important questions and subjects to consider.

Resource Title	Description	How To Access	Best Uses
Family Assessment for Pediatric Clients Receiving Home Care	A basic family assessment tool for clinicians to use in the home, specific to pediatric patients and their families.  Presented in two versions: Either a list of questions to guide conversations, or a table of questions home health professionals can chart on directly.	Available from the IWK Health Centre: <a href="http://www.iwk.nshealth.ca/page/pediatric-resources-home-health-professionals">http://www.iwk.nshealth.ca/page/pediatric-resources-home-health-professionals</a>	Routine use for initial in-home assessments, and ongoing in-home reassessment for patients with basic and/or complex health needs.
Sibling Support	A website from Seattle Children's Hospital with information and resources on how to support siblings who have a brother or sister with special health care needs.	<a href="https://www.siblingsupport.org/">https://www.siblingsupport.org/</a>  The resources section has documents such as "What siblings would like parents and service providers to know" and "How to let young siblings know you care".	Quick and in-depth learning options available.



## References

- About Kids Health. (n.d.) About Kids Health. Retrieved from <https://www.aboutkidshealth.ca/>
- AUS Med. (2015). Communicating with Children in Healthcare. Retrieved from <https://www.youtube.com/watch?v=†OZDAVj3X5Y>
- BC Children's Hospital. (n.d.) Dressing changes. Retrieved from <http://www.bcchildrens.ca/Child-Life-site/Documents/Dressing%20Change%20Prep%20Book%202018.pdf>
- BC Children's Hospital. (n.d.) Ways you can help children cope during treatments and procedures. Retrieved from <http://www.bcchildrens.ca/Child-Life-site/Documents/Tips%20for%20Caregivers.pdf>
- Canadian Pediatric Society. (2018). Global developmental delay and intellectual disability. Retrieved from <http://pedscases.com/global-developmental-delay-intellectual-disability-cps-podcast>
- Canadian Pediatric Society. (2018). Pediatric palliative care. Retrieved from <https://www.pedscases.com/specialty-area/palliative-care>
- Children's Healthcare Canada and In-Gauge. (2017). If you only knew: The voices of families of children with complex care needs. Retrieved from [https://www.youtube.com/watch?v=ghsKm1Zm6ro&list=PLdQfM1\\_yW0PtI3s0sy0ZGBvuUyXUZ1bHG](https://www.youtube.com/watch?v=ghsKm1Zm6ro&list=PLdQfM1_yW0PtI3s0sy0ZGBvuUyXUZ1bHG)
- Children's Healthcare Canada. (n.d.) Medically complex children. Retrieved from [https://images.squarespace-cdn.com/content/v1/5bd8a55e4eddec150a2acdb/1544463180836-VT72S3T72SC2CNRCVLMH/ke17ZwdGBToddI8pDm48kJZW6zhob9awPz640NRRJcR7gQa3H78H3Y0txjaiv\\_ofDoOvxcdMmMKkDsyUqMSsMWxHk725yiiHCCLfrh8O1z4YTzHvnKhyp6Da-NYroO-W3ZGjoBKy3azqku80C789I0pa5utEcoDWpn0hH27EPHs6YpqR16Q5b3RWnth7I4iloUNq0q9F7nstxtmKTcbqtlw/MedicallyComplexChildrenPHactSheet.png](https://images.squarespace-cdn.com/content/v1/5bd8a55e4eddec150a2acdb/1544463180836-VT72S3T72SC2CNRCVLMH/ke17ZwdGBToddI8pDm48kJZW6zhob9awPz640NRRJcR7gQa3H78H3Y0txjaiv_ofDoOvxcdMmMKkDsyUqMSsMWxHk725yiiHCCLfrh8O1z4YTzHvnKhyp6Da-NYroO-W3ZGjoBKy3azqku80C789I0pa5utEcoDWpn0hH27EPHs6YpqR16Q5b3RWnth7I4iloUNq0q9F7nstxtmKTcbqtlw/MedicallyComplexChildrenPHactSheet.png)
- Children's Healthcare Canada. (2015). Distraction toolkit. Retrieved from <https://ken.childrenshealthcarecanada.ca/xwiki/bin/view/Paediatic+Pain/Distractio+Toolkit>
- Children's Healthcare Canada. (2015). The chronic pain assessment toolbox for children with disabilities. Retrieved from <https://youtu.be/HDGXmsDn25k>
- Children's Healthcare Canada. (2016). It's just a poke (prick), right? Needle pain prevention in pediatrics. Retrieved from <https://youtu.be/uSdHlvvuEPo>
- CHOC Doc's Blog. (2017). 5 tips on connecting with your pediatric patients. Retrieved from [https://docs.chocchildrens.org/5-tips-connecting-pediatric-patients/?\\_\\_hstc=45511931.a1d28](https://docs.chocchildrens.org/5-tips-connecting-pediatric-patients/?__hstc=45511931.a1d28)

50e30e07de78b44b1421d65dad6.1569105712267.1569105712267.1569105712267.1&\_\_hssc=45511931.4.1571079881497&\_\_hsfp=3570664279&\_ga=2.260191693.1319690361.1571079899-963079020.1569105724

Cohen, E., Kuo, D. Z., Agrawal, R., Berry, J. G., Bhagat, K. M., Simon, T. D., & Srivastava, R. (2011). Children with medical complexity: An emerging population for clinical and research initiatives. *Pediatrics*, 127(3), 529-538. <http://dx.doi.org/10.1542/peds.2010-0910>

Complex Care at Home for Children. (n.d.) Complex care at home for children. Retrieved from <https://complexcareathomeforchildren.com/>

Connected Care. (n.d.) About Kids Health: Connected Care learning hub. Retrieved from <https://www.aboutkidshealth.ca/connectedcare>

Courageous Parents Network. (2018). Courageous parents network. Retrieved from <https://courageousparentsnetwork.org/>

Elias, E. R., Murphy, N. A., & The Council on Children with Disabilities. (2012). Home care of children and youth with complex health care needs and technology dependencies. *Pediatrics*, 129(5), 996-1005. <http://dx.doi.org/10.1542/peds.2012-0606>

Hagan, J. F., Shaw, J. S., & Duncan, P. M. (Eds.). (2017). *Bright futures: Guidelines for health supervision of infants, children, and adolescents (4<sup>th</sup> ed)*. American Academy of Pediatrics [E-Book]. Retrieved from [https://brightfutures.aap.org/Bright%20Futures%20Documents/BF4\\_CYSHCNHealth.pdf](https://brightfutures.aap.org/Bright%20Futures%20Documents/BF4_CYSHCNHealth.pdf)

Holland Bloorview. (2019). The chronic pain assessment toolbox for children with disabilities. Retrieved from <http://www.hollandbloorview.ca/research-education/knowledge-translation-products/chronic-pain-assessment-toolbox-children>

IWK Health Centre. (2019). Pediatric resources for home health professionals. Retrieved from <http://www.iwk.nshealth.ca/page/pediatric-resources-home-health-professionals>

IWK Health Centre. (2014). The power of a parent's touch. Retrieved from <https://www.youtube.com/watch?v=3nqN9c3FWn8&feature=youtu.be>

IWK Health Centre. (2013). It doesn't have to hurt. Retrieved from <https://youtu.be/KgBwVSYqfps>

Jordan, M., Keefer, P. M., Lee, Y. L. A., Meade, K., Snaman, J. M. Wolfe, J., ... & Rosenberg, A. (2018). Top ten tips palliative care clinicians should know about caring for children. *Journal of Palliative Medicine*, 21(2), 1783-1789. <http://dx.doi.org/10.1089/jpm.2018.0482>

Kids Grief. (2017). Kids grief: Talking with kids & teens about dying and death. Retrieved from <https://kidsgrief.ca/>

Levetown, M. & The Committee on Bioethics. (2008). Communicating with children and families: From everyday interactions to skill in conveying distressing information. *Pediatrics*, 121(5), e1441-e1460. <http://dx.doi.org/10.1542/peds.2008-0565>

Lloyd, J. (2016). Talking to your pediatric patients: Tips from a pediatric hospitalist. Retrieved from <https://medschool.ucla.edu/body.cfm?id=1158&action=detail&ref=806>

Mack, J. W., & Wolfe, J. (2006). Early integration of pediatric palliative care: For some children, palliative care starts at diagnosis. *Current Opinion in Pediatrics*, 8, 10-14. <http://dx.doi.org/10.1097/01.mop.0000193266.86129.47>

Open Pediatrics (n.d.) Open Pediatrics. Retrieved from [www.openpediatrics.org](http://www.openpediatrics.org)

Ophanet. (2019). Orphanet: The portal for rare diseases and orphan drugs. Retrieved from <https://www.orpha.net/consor/cgi-bin/index.php>

Pexels. (n.d.) Pexels. Retrieved from <https://www.pexels.com/>

Royal Children's Hospital Melbourne. (2019). Reducing your child's discomfort during procedures. Retrieved from [https://www.rch.org.au/kidsinfo/fact\\_sheets/Reduce\\_childrens\\_discomfort\\_during\\_tests\\_and\\_procedures/](https://www.rch.org.au/kidsinfo/fact_sheets/Reduce_childrens_discomfort_during_tests_and_procedures/)

Sibling Support. (2018). Sibling support. Retrieved from <https://www.siblingsupport.org/>

The Children's Hospital of Philadelphia. (2019). The Children's Hospital of Philadelphia. Retrieved from <https://www.chop.edu/>

Tommet, P. A. (2003). Nurse-parent dialogue: Illuminating the evolving pattern of families with children who are medically fragile. *Nursing Science Quarterly*, 16(3), 239-246. <http://dx.doi.org/10.1177/0894318403016003015>

Treadwell-Deering, D. (2015). Age appropriate communication and developmental issues. In D. L. Palazzi, M. I. Lorin, T. L. Turner, M. A. Ward, & A. G. Cabrera. *Communicating with pediatric patients and their families: The Texas Children's Hospital guide for physicians, nurses and other healthcare professionals* (pp. 26-37). Retrieved from <https://www.bcm.edu/departments/pediatrics/patient-communication-guide>

University of Illinois Children's Hospital. (2017). Distraction in action: Helping your child during medical procedures. Retrieved from <https://www.youtube.com/watch?v=D6GSPUVh2k0&feature=youtu.be>

Unity Point at Home. (2014). 11 ways to communicate to children with special needs. Retrieved from <https://www.unitypoint.org/homecare/article.aspx?id=538d6c28-b8c1-488e-bdc9-6ff5900ccfff>