



# Transitioning to Adult Care with a GJ or Combination G/GJ Tube

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# Transitioning to adult care with a feeding tube

Reviewed by SickKids Staff

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Find out what needs to be done to prepare for the transition to the adult health-care system and what to expect from the new health-care team.

#### Key points

- Some teens with feeding tubes will be able to manage the transition to adult care on their own, while others will need support from their parents and caregivers.
- · Most paediatric patients will transition to adult care around their 18th birthday.
- Before transitioning, you will need to be able to manage tube and stoma care and have a primary care provider who will become your main contact and care coordinator.
- You will meet with the G Tube Feeding Program nurses before transition to make sure you know how to change the tube, care for stoma issues, review your transition package, and have a final tube and skin assessment or tube change if needed.

Some teens with a feeding tube will be able to manage their own transition to adult care, while others will need help from their parents or caregivers.

# Transitioning to the adult health care system

Most paediatric patients will transition to the adult health care system around the time they turn 18. Preparing to transition to the adult health care system starts several years before then.

To learn more about transitioning to adult care, and the differences between paediatric and adult care, please see the page "<u>Transitioning to adult care (for teens)</u>" or "<u>Transitioning to adult care (for parents)</u>".

# Transitioning with a G, GJ, combination G/GJ or J tube

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At SickKids, there are many knowledgeable and easily accessible health-care providers to help with your feeding tube. In the adult health-care system, this may not be the case. There is usually no adult G Tube Feeding Program and you cannot access the paediatric G Tube Feeding Program after 18 years of age. You will need to learn how to navigate the adult health-care system to get help with tube and stoma issues.

Your primary health-care provider (i.e., family physician, nurse practitioner) will be your main contact and care coordinator. It is important to engage them in tube and stoma care right away. This can be done in the following ways:

- · Discuss stoma and tube health with them at appointments
- Update them when there are issues with the skin or tube and share how the issue was managed or treated
- · Involve them in skin and tube issue management
- While you are a SickKids patient, encourage your primary care provider to connect with the G Tube Feeding Program so they can ask questions about tube care and how best to support the transition to adult care

If you have a pediatrician, it will be important to find a family doctor before you turn 18 years old so that they can get to know you and your feeding tube needs.

Home care nursing, including wound care nurses, may also be accessible for complex stoma issues. Speak to your primary care provider about whether a referral for these services would be appropriate.

# Changing the feeding tube

If you or your child have a <u>balloon-style G tube</u>, make sure you know how to change it by yourself, as this will be an expectation before and after 18 years old. Reach out to the G Tube Feeding Program if you have not yet been taught to do this.

If you or your child have a balloon-style GJ, such as a <u>Mickey J</u>, or a <u>balloon-style combination</u> <u>G/GJ</u> tube, you will need to access an interventional radiology (IR) department at an adult hospital for tube changes. Adult IR departments are different from paediatric departments in a few ways:

- Adult IR departments do not typically offer sedative medications to sleep for tube exchanges.
- Parents will not be allowed in the room during a procedure.

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 Adult IR departments may not have the same tube you had at SickKids, so it's possible the tube may change at some point.

Your primary health-care provider or gastrointestinal (GI) specialist will manage the referral to the adult IR department.

If there is an urgent issue with the tube before you are connected to the adult IR department, you may need to go to the emergency department of the hospital. If possible, go to the emergency department of the hospital where you will be followed or where your GI specialist practices.

The <u>AboutKidsHealth Tube Feeding Learning Hub</u> will continue to be a resource for you and your family, with videos and helpful tricks and tips for managing your stoma and tube. Your primary care provider can also learn more about managing your stoma and tube at <u>Academy</u> Online.

# Transition appointment

Before your or your child's 18th birthday, you will have an in person or virtual (video call) transition appointment in the G Tube Clinic with one of the G Tube Feeding Program nurses. At this appointment:

- The tube and skin will be assessed for the last time at SickKids. Treatment will be recommended, if needed.
- · You will show the nurse how to exchange your balloon G tube.
- If you have a GJ or combination G/GJ tube, a last tube exchange in IGT will be organized.
- You will review your transition package, which includes helpful information and resources for both you, your family, and your primary health-care provider.
  - The transition package for patients with G tubes can be accessed here: <u>Transition</u>
     <u>Package G Tubes</u>
  - The transition package for patients with a GJ tube or combination G/GJ tube can be accessed here: <u>Transition Package - GJ and Combination G/GJ tubes</u>
- Prepare for this appointment by having a list of questions or concerns ready to share. It is
  normal to have questions or concerns that you may not want to share in front of your
  parent(s). Set aside some time to speak with the G Tube nurse alone. Here are some tips
  for talking with your health care team.

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The G Tube Feeding Program nurses will send the transition package and visit note to your primary health-care provider directly after the appointment.

#### At SickKids

For more information and resources related to transition, visit: <a href="https://www.sickkids.ca/en/patients-visitors/transition-adult-care/">https://www.sickkids.ca/en/patients-visitors/transition-adult-care/</a>

# **Transition packages**

Transition Package - G Tubes

Transition Package - GJ and Combination G/GJ tubes

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# **Preparing for Transition – Start Early!**

#### Until 14 years old

- Recognize stoma and tube issues and connect with appropriate team to support management.
- Start to manage basic stoma and tube issues independently.
- Engage primary care provider(s) in discussions about the stoma and tube.
- Know your resources.

#### G and J tubes:

 Participate in changing the balloon tube.

#### GJ and Combination G/GJ Tubes:

 Engage appropriate team members to coordinate IGT tube checks/changes.

#### 14 years old

- Manage basic stoma and tube issues independently.
- Continue to engage primary care provider(s) to manage basic skin and tube issues independently.
- Start discussing transition to adult care with G Tube Feeding Program, primary care provider and specialty medical team.
- Find a family doctor.
- Look into Substitute
   Decision Maker and
   Consent. (CCKO toolkit)
- Know your resources.

#### G and J tubes:

 Change balloon tubes independently.

#### GJ and Combination G/GJ Tubes:

 Engage appropriate team members to coordinate IGT tube checks/changes.

#### 14 - 17 years old

- Manage basic stoma and tube issues independently.
- Continue to engage primary care provider(s) to manage basic skin and tube issues independently.
- Annual touch base with G Tube Feeding Program about transition needs.
- Start applications for adult financial and developmental supports.
- Start referrals to adult medical specialists.
- Know your resources.

#### G and J tubes:

 Change balloon tubes independently.

#### GJ and Combination G/GJ Tubes:

 Engage appropriate team members to coordinate IGT tube checks/changes.

#### 17 - 18 years old

- Manage basic stoma and tube issues independently.
- Primary care provider(s) to manage basic skin and tube issues independently.
- Meet with G Tube Feeding Program for final transition meeting to review transition package.
- Consider a tract length remeasurement, if needed.
- Ensure all tube related prescriptions are completed.
- Transfer medical care from pediatrician to family doctor.
- Discuss and transfer home care needs with LHIN.
- · Know your resources.

#### G and J tubes:

 Change balloon tubes independently.

#### GJ and Combination G/GJ Tubes:

- G Tube Team will support first referral to an adult interventional radiology department for future tube changes.
- Engage primary care provider for future referrals.

# **Your Tube History**

Primary tube insertion date: Inserted by:

**Reason for G Tube Insertion:** 

**Tube history:** 

**Current tube (circle one)** 

Avanos MIC Jejunal



Avanos MIC-Key GJ Tube



**AMT GJet** 



Avanos
MIC-Key Combination G/GJ



Avanos
MIC Combination G/GJ



Tube size (FR):

Tract length (cm):

Distal (internal) length (cm):

# **Tube Troubleshooting 101**

# My feeding tube fell out

Always have your emergency kit on hand



Insert a foley catheter ASAP



Instructions and videos for inserting a foley catheter: <a href="www.aboutkidshealth.ca/tubefeeding">www.aboutkidshealth.ca/tubefeeding</a> under "What to do if my child's feeding tube accidentally falls out"

# My feeding tube is blocked



- Clean and/or replace all extensions and adaptors.
- Flush with warm water.
- Using a 1mL, 3mL, and 5mL syringe, flush the tube with warm water using a pulsating (push-pull) motion.
- <u>Use activated pancreatic enzymes (prescription required).</u>
- If the tube remains blocked, change the tube.



# My feeding tube's balloon is broken

- Tape the tube to stop it from falling out.
- Continue using the tube as long as you are not vomiting.
   If you are vomiting, contact the go to the emergency department.
- Change the tube at home, if possible.



# My feeding tube is too tight or too loose

- Adjust the balloon volume, as per manufacturer's recommendations.
- See <u>www.aboutkidshealth.ca/tubefeeding</u> for more information

# **Urgent Reasons To Go To Your Local Emergency Department**

- The tube is broken and you <u>cannot</u> manage hydration and give essential medications.
- The tube is blocked and you <u>cannot</u> manage hydration and give essential medications.
- Your tube has fallen out and you cannot insert a tube into the tract.
- You have the following symptoms immediately after, or within 24 hours of, inserting a Foley catheter:
  - Bloated stomach and/or severe pain
  - Vomiting, coughing, or gagging
  - Sudden high fever
  - Diarrhea
  - Breathing problems
- You are concerned about intussusception.
- You are concerned about tube migration.

# Intussusception

<u>Intussusception</u> may occur around the tube. Intussusception refers to when one part of the small bowel slides into the next part. This may lead to a bowel obstruction at the tip of the tube. Large GJ/Combination G/GJ tubes and/or normal movements of the bowels may cause intussusception.

With intussusception, you may experience:

- discomfort and feeding intolerance (vomiting when fed)
- vomiting bile (dark green fluid)
- diarrhea or blood in the stool

This is diagnosed with an abdominal ultrasound and may require bowel rest until the intussusception resolves. Do not use the tube for feeding until intussusception is ruled out.

# **Tube Migration**

If your tube has moved out of the small intestine and into the stomach, you may experience:

- increased vomiting
- vomiting formula
- gagging and retching
- abdominal discomfort or pain
- bloated stomach
- diarrhea
- leaking of formula from the stoma

The position of the tip of tube will need to be confirmed by an interventional radiologist using image guidance. Do not use the tube until the tube position is confirmed.

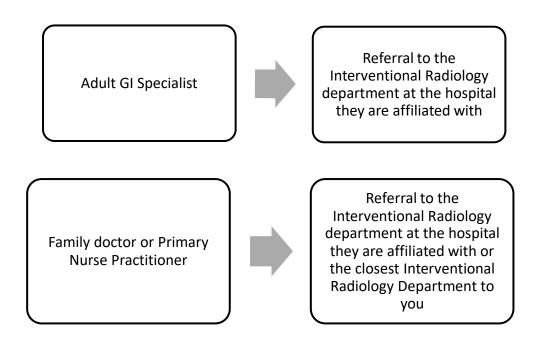
#### If you believe you have intussuscepted or that the tube has migrated:

<u>During business hours</u>, contact the radiology department where your primary health care provider or GI specialist referred you and try to coordinate an appointment.

<u>After hours, on weekends or on holidays</u>, go to the Emergency Department of the hospital where your primary health care provider or GI specialist referred you.

# **Referral Process for Non-Urgent Tube Changes**

Referrals for non-urgent tube changes at an adult Interventional Radiology department <u>must come from your primary health care provider</u>. This may be your family doctor, primary nurse practitioner or your adult GI specialist.



The referral should include the following:

- A medical imaging requisition
- A brief summary of your medical history
- Detailed information about your current feeding tube
  - Tube type (G, GJ, J)
  - Tube brand name
  - Tube French (FR) size
  - Tube length (tract length and/or internal length in CM)

Once the referral is sent, the Interventional Radiology department or their booking team will contact you with a booking.

The first referral to an adult radiology department will be sent by the G Tube Feeding Program. This will ensure the tube information, indications for tube use and tube history are accurately reflected in the referral.

# **Managing Stoma Issues**

Your family doctor, primary nurse practitioner or home care nursing/wound care specialist will support you with stoma related issues such as:

#### **Granulation tissue**













**Bacterial Infection** 











**Fungal infection** 



**Contact dermatitis from leakage** 







For more information, your primary care provider can visit:

AboutKidsHealth Tube Feeding Hub – click <u>here</u>.

Academy Online Learning e-Module – click <u>here</u>.

Enteral Tube Stoma Assessment Clinical Practice Guideline – click <u>here</u>







# **Your Stoma History**

I have had a:		
■ Bacterial stoma infection		
Signs and symptoms were:		
Most effective treatment(s) were:		
Stoma leakage		
Signs and symptoms were:		
20 . (6 .:		
Most effective treatment(s) were:		
☐ Granulation Tissue		
Signs and symptoms were:		
o.g and of infrastruction		
Most effective treatment(s) were:		
• •		

# When to see your GI Specialist or Primary Care Provider

- To help you manage general medical concerns and your medications.
- You are experiencing feeding intolerance not related to the tube.
- You are experiencing oral feeding issues.
- You need orders for homecare nursing.
- You have concerns about your weight, nutrition, or diet changes.
- To help you manage stoma issues such as infection, granulation tissue and mild leakage.
- To discuss transitioning from a G to a GJ tube.
- To discuss transitioning from a GJ to a G tube.
- To discuss permanent removal of a G or GJ tube.

# **Other Resources**

If you have questions/concerns about:	You should call:
Tube and feeding supplies	Medical Supply Store
Feeding pump	Where you purchased your pump or pump company

<sup>\*\*</sup>Social media groups can be very supportive throughout your G Tube journey. You may also be able to access supplies and equipment through these groups at lower costs.\*\*

# **Permanent Tube Removal**

If you are considering permanently removing the feeding tube, it is important to have discussions with the team that manages your nutrition, growth and overall medical care. This may be your GI specialist, your family doctor or nurse practitioner.

Consider the following questions before permanently removing your feeding tube:

- Can I take everything by mouth, all the time? This includes nutrition, hydration and medications.
- Have I been taking everything by mouth for at least 2-3 months?
- Have I been sick and not needed to use my feeding tube?
- Do I have any upcoming procedures or surgeries that would affect my ability to eat by mouth?

If you are able to take everything by mouth, all the time, do not need to use your feeding tube when you are sick and does not have any upcoming procedures or surgeries that will affect you eating, you may be ready for permanent tube removal.

For more information about permanent tube removal, click <u>here</u>.

GJ and Combination G/GJ tube are generally removed by a G Tube Specialist or Interventional Radiologist. Your primary care provider can refer you to the closest adult interventional radiology team to discuss.

# **Vendors for Equipment and Supplies**

Calea	Mississauga, ON	905-624-1234	https://www.calea.ca/en/contact-us/
Can Med Direct Inc.	Markham, ON	1-855-422-6633	https://www.canmeddirect.ca/
Concord Specialty Pharmacy	Concord, ON	905-738-5155 or 1-855-738-5155	www.concordsp.ca
Durham Medical	Oshawa, ON	905-728-1112 press #2	https://durhammedical.ca/
Glen Erin Pharmacy	Mississauga. ON	905-828-1980 or 1-866-446-6302	https://glenerinpharmacy.com/
KidCare Pharmacy	Ottawa, ON (at CHEO)	613-737-2316	https://www.cheo.on.ca/en/visiting- cheo/pharmacy-kidcare.aspx
Medigas	Various locations across ON	1-866-446-6302	https://www.medigas.com/en
Melekare	London, ON	519-518-6353	www.melekare.ca
Ontario Home Health	Various locations across ON	1-800-661-1912	https://www.ontariohomehealth.ca/
Ontario Medical Supply	Various locations across ON	1-800-267-1069	https://www.oms.ca/
Maxim Medical Supplies	Windsor and Tecumseh, ON	519-977-7200	https://maximmedical.ca/
Starkman Health Care Depot	Toronto, ON	416-534-8411	https://starkmans.com/
Specialty Food Shop	Toronto, Ontario (at Sick Kids)	1-800-737-7976 or 416- 813-5294	www.specialtyfoadshop.ca
Well Wise by Shoppers Drug Mart	Various locations across ON	1-866-220-3837	https://shop.wellwise.ca/
Wellness & Mobility Inc.	Various locations across ON	519-250-4390	https://wami.ca/
Yurek Pharmacy & Home Health Care	London, ON	519-963-1142	www.yurekpharmacy.com

#### **Dear Emergency Room Staff**

This letter is to inform you that this patient has a gastrojejunostomy (GJ) or combination gastrostomy/gastrojejunostomy (combination G/GJ) tube that has been accidently dislodged. A Foley catheter needs to be inserted into the patient's stoma/tract as soon as possible to prevent stoma and tract stenosis or permanent closure. This requires immediate attention.

Tube Information				

See <u>www.aboutkidshealth.ca/tubefeeding</u> for step-by-step how-to videos.

Gather the following supplies. Parents often have all these items in their emergency kit.



#### **Foley catheter**

- 1. Wash the stoma with soap and water
- 2. Measure the tip of the Foley catheter against your index finger (4-6cm)
- 3. Lubricate the tip of the Foley catheter
- 4. Insert the measured length of the tube into the stoma
- 5. Tape the tube to the abdomen

#### DO NOT use the tube until placement is verified or exchanged using fluoroscopy in a radiology department.

Alternate methods for feeding and medication administration need to be arranged (i.e. NG, NJ, PIV) until the tube can be replaced.

# **Funding Resources**

As you turn 18, there may be different funding opportunities available to support you. Here are some examples to consider:

Assistive Devices Program (ADP) provides a grant to help cover the costs of feeding pumps, feeding bags, tubes and catheters and accessories for those with a valid OHIP card and a long-term physical disability requiring enteral feeding for more than 6 months. This would have been arranged when you got your very first tube and you must reapply for funding in the future and your family doctor can support you with this. <a href="https://www.ontario.ca/page/assistive-devices-program">https://www.ontario.ca/page/assistive-devices-program</a>

**Developmental Services of Ontario "Passport Program"** is the single point of access for adult developmental services in Ontario. The program supports costs related to community participation and activities of daily living, caregiver respite, person-directed planning and administration for those with intellectual disabilities. It is important to register at 16 years old for funding to start at 18 years old. https://www.dsontario.ca/

#### **Disability Tax Credit (DTC)**

The DTC is a non-refundable tax credit that helps persons with disabilities or their supporting persons reduce the amount of income take they may have to pay. Your eligibility is based on your income tax information. <a href="https://www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/disability-tax-credit.html">https://www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/disability-tax-credit.html</a>

**Ontario Disability Support Program** provides income support, benefits for health costs and other disability supports for those 18 years and older. It is important to apply when you are 17.5 years old for funding to start at 18 years old.

https://www.ontario.ca/page/ontario-disability-support-program

#### **Registered Disability Savings Plan (RDSP)**

An RDSP is a savings plan intended to help parents and others save for the long term financial security of a person to is eligible for the Disability Tax Credit.

https://www.canada.ca/en/revenue-agency/services/tax/individuals/topics/registered-disability-savings-plan-rdsp.html

For help navigating these opportunities, consider reaching out to the Sick Kids Resource Navigation team <a href="https://www.sickkids.ca/en/patients-visitors/financial-legal-assistance/">https://www.sickkids.ca/en/patients-visitors/financial-legal-assistance/</a>