



CHILD GASTROSTOMY

Decision Guide

INTRODUCTION

You are facing the decision about having a gastrostomy (GTube) tube for your child. This guide will take you through steps to make it easier for you. The answers will come from yourself, any tests that can be done for your child, and from talking to the team who is caring for your child and the team who gives “second opinions”.

It is helpful if there is more than one family decision maker that each answers these questions on their own.

Some questions to ask yourself as you work through this process:

1. How are you feeling right now?
2. Which reasons to choose each option matter most to you and your family?
3. What else do you need to prepare for decision making?
4. What are the next steps?

STEP I: UNDERSTAND YOUR CHILD

In most cases when a GTube is being considered, it is important to take time to review the decision carefully. There are four general reasons why a GTube is considered:

1. Abnormalities of the mouth, esophagus, stomach, or intestines that are congenital (present from birth) or became abnormal due to illness or injury
2. Sucking and swallowing disorders, which are often related to prematurity, brain injury, developmental delay or certain neuromuscular conditions, like severe cerebral palsy. The child may be at risk for aspiration and/or is having aspiration pneumonias and lung disease because of aspiration
3. The child has an illness or condition where they cannot eat enough calories to maintain their nutrition
4. Extreme difficulty taking medicines

What type of nutritional support is your child getting now?

- Long tube through the nose (NG or NJ tube) with feeds
- Oral feeds that are thickened
- Oral feeds with a regular texture
- Other: _____

Why does your child need nutritional support?

- Illness or injury that has led to problems with the brain, nerves or muscles needed for eating
- Inability to eat enough calories by mouth
- Illness or injury that requires a large amount of calories
- Weakness of the muscles that affect swallowing.

What is your child's future need for nutrition support likely to be?

- Temporary and likely to improve.
- Permanent and likely to remain the same.
- Permanent and likely to get worse.
- Not known whether it will get better or worse over time.

Rate your child's quality of life right now.

- Excellent - No pain or discomfort and is able to interact with people and enjoy life.
 - Good - Some pain or discomfort at times but is able to interact with people and enjoy life.
 - Poor - Pain or discomfort much of the time and very little ability to interact with people and enjoy life.
 - Very poor – Pain or discomfort most of the time and no indication of any ability to interact with people and enjoy life.
-

What are your hopes, wishes and concerns for your child and are they achievable?

Hopes	Wishes	Concerns
		
<i>Achievable?</i>	<i>Achievable?</i>	<i>Achievable?</i>
		

STEP 2: EXPLORE OTHER OPTIONS

The options for your child *may* include:

- Surgery or different medicine to improve GERD or correct or change anatomic problems.
 - Review the pros and cons of doing and not doing each option that is possible for your child.

- Keep giving the current nutritional support and wait to see what will happen with their condition.
 - Is there still a chance for improvement?
 - Has there been enough time?
 - Is the child having complications such as sinus infections or frequent tube dislodgements?

- Comfort care which includes continuing to feed your child orally. Decide on what to do and what not to do for your child. Your child's length of time is limited, and their comfort is the most important thing.
 - What are your goals for your child?

Who did you include in the discussions?

- You and your family
- Child's Pediatrician
- Hospital physician
- Surgeon(s)

- Pediatric Gastroenterologist
- Pediatric Pulmonologist
- Nurse (*include those who know your child best*)
- Feeding Therapist
- Social Worker
- Spiritual Care Worker (preferably from your own community)
- Other people:

Options for your child are:

- Surgery or different medicine to improve GERD or correct or change anatomic problems: _____
- Continue to support your child the way they are currently being supported and wait to see which way child's condition will go.
- Gastrostomy

How clear are the options to you?

- Very clear
- Mostly clear – I would like to discuss them further.
- Not clear – I need to discuss with more people or need more time and explanations to understand them.

List the options that you need to talk more about:

Do you understand the reasons to choose each option? Yes No

Do you feel pressure to choose any of the options? Yes No

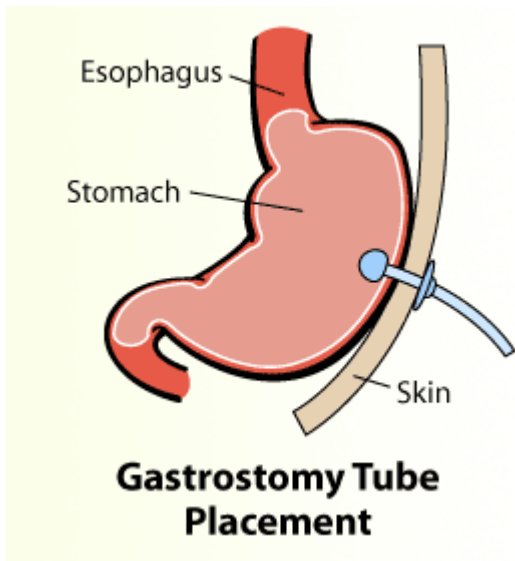
If so, describe the pressure:

Do you have a preference for any one option? Yes No

Which one and why?

STEP 3: UNDERSTAND THE GASTROSTOMY OPTION

Gastrostomy tubes are feeding tubes placed through the abdomen into the stomach. The pediatric surgeon places a gastrostomy tube in the operating room under general anesthesia. This operation is usually done through a small incision (cut) on the abdomen. Gastrostomy tubes are used to give children formula, liquids, and medicines.



Some children are candidates for a Nissen Fundoplication at the same time as the gastrostomy. The Nissen prevents your child from refluxing formula/food back into the esophagus or lungs. It takes the top curvature of the stomach and wraps it around the lower portion of the esophagus, like a bun around a hot dog. Its pro's and cons are listed after the Gastrostomy pro's and cons.

It is not always known how long a child may need a gastrostomy once it is placed, but it is important to get input from as many people as possible.

If gastrostomy surgery is performed, your child will be in the hospital for approximately 2-6 days or longer depending on your child's illness (2 days for G-button, 3-6 days for G-button/Nissen).

The procedure:

The risks any time a child is given medication are:

- Problems breathing
- Reactions to medications

The risks for any surgery are:

- Bleeding
- Infection

Extra risks that can occur during or after surgery include:

- Damage to the stomach or intestines

Do you understand the risks and legalities of the procedure for your child?

Yes No

Your child's gastrostomy will most likely be:

- Needed for a short time but still in place when the child is otherwise ready to go home.
- Needed for many years.
- Needed for life.

PROS of a GTube

- Can reduce risk of aspiration
- Moves tubes and tape away from face.
- Creates a more "stable" feeding tube that is less prone to accidental removal than an NG or NJ tube.
- Buttons can last between 3-6 months
- It can reduce the time families spend feeding and allow for more positive interactions between parent and child
- If your child is not feeding you can cover the tube with clothing, making it unnoticeable.

List the pros of a GTube for your child:

CONS of a GTube

- Involves a surgical procedure to place
- It can still be pulled out or dislodged
- GTubes need to be vented to release gas from the stomach
- GTubes can clog
- GTubes can sometimes make GERD (reflux) worse
- Your child might develop granulation tissue around the stoma, which can look like blisters and redness
- Loss of oral feeding (if applicable) can cause sadness and grief in patient and family

List the cons of a GTube for your child:

PROS of a Nissen

- Can reduce or prevent aspiration
- Can reduce or prevent vomiting from reflux which can lead to better weight gain
- Often can be done laparoscopically
- If vomiting has created significant discomfort, it can improve quality of life

List the pros of a Nissen for your child:

CONS of a Nissen

- When your child needs to throw up he/she may retch, which is uncomfortable
- The Nissen can slip or loosen which can require additional surgery
- Some children continue to vomit thru their Nissens or continue to have reflux even after the procedure
- Some children develop bloating problems after a Nissen where they require a lot of venting of the GTube
- Some children develop dumping syndrome as a result
- Children with poor intestinal motility may do poorly with a Nissen

List the cons of a Nissen for your child:

Caring for a child with a gastrostomy includes providing the basic care to the child plus knowing how to manage the care of a GTube. This will include learning:

- How to give foods and medicine thru the gastrostomy
- Skin care for the stoma and how to manage problems or issues with the stoma.
- How to replace the GTube, what to do if it comes out accidentally and what to do if a new one won't go in easily.
- What to do if the GTube becomes plugged or blocked.
- Managing equipment such as a feeding pump if it is needed.

To get a better idea of what GTube care is like, the Gastrostomy teaching guide goes into more detail.

The conditions to go home with a gastrostomy include:

- At least 1 caregiver (ideally 2 or more) are trained in care of the child and gastrostomy equipment.
- Reasonable proximity to health care workers who can provide care to the child in case of emergency.
- Adequate respite support for the caregivers is available.

Every family will have different options that are available to them. Discuss with the team which are realistic for you.

Caring for a child with a gastrostomy at home requires:

- Presence of a trained caregiver. The child cannot be left in the care of a "babysitter" who is not trained and able to give both routine and emergency care.
- Having a plan for how to get emergency help if needed.
- Consideration of the increased costs to the family for items not provided by the health care system including: cleaning supplies for equipment, home supplies used by caregivers.

Which of the following is most true about your home:

- My child can safely be care for there.
- With some changes my child can safely be cared for there. (i.e. Teaching, modifications, adjustments, safety issues, insurance)
- I am not sure if my child can safely be cared for there.
- My child cannot be safely cared for there.

Which of the following is most true about your community:

- My child can safely be cared for there.
- With some changes, my child can safely be cared for there (i.e. Teaching, modifications, adjustments).
- I am not sure if my child can safely be cared for there.
- My child cannot be safely cared for there.

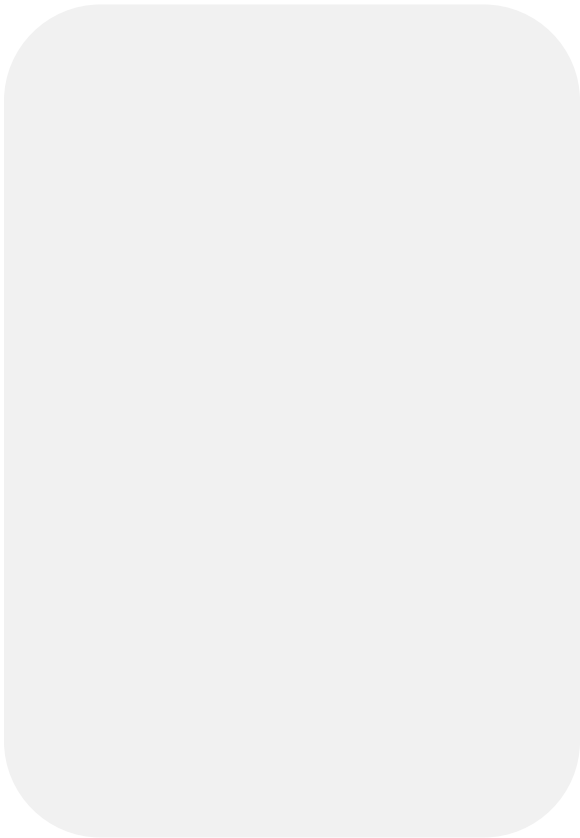
Which of the following is most true about your family’s ability to deal with the increased costs:

- We will be able to manage the increased costs.
- With some help we should be able to manage the increased costs.
Need discussion with social worker.
- I am not sure if we can handle the increased costs.
- Without some considerable change in circumstances we will not be able to manage the increased costs.

After discussion of the care needs of a child with a gastrostomy how prepared do you feel to be your child’s caregiver?

- Very prepared – I am able to care for my child with a gastrostomy
- Somewhat prepared – with more teaching and practice I would be ready to care for my child with a gastrostomy
- Not prepared – I am unsure of whether I will be able to care for my child with a gastrostomy
- Not prepared – I do not think that I will be able to care for my child with a gastrostomy

List the people who may be able to learn to care for your child:



STEP 4: MAKING THE DECISION

Are there any values that you have that are impacting your decisions?

In the table below rate your child's quality of life for each of the options that apply to your child:

- Not An Option: there are no surgical or medical options.
- Excellent – No pain or discomfort and is able to interact with people and enjoy life.
- Good - Some pain or discomfort at times but is able to interact with people and enjoy life.
- Poor – Pain or discomfort much of the time and very little ability to interact with people and enjoy life.
- Very poor – Pain or discomfort most of the time and no indication of any ability to interact with people and enjoy life.
- Don't know – not sure if this is an option

Surgical or Medical Treatment	<input type="checkbox"/> Not An Option	<input type="checkbox"/> Excellent	<input type="checkbox"/> Good	<input type="checkbox"/> Poor	<input type="checkbox"/> Very Poor	<input type="checkbox"/> Don't Know. Need more information
Continue Present Support	<input type="checkbox"/> Not An Option	<input type="checkbox"/> Excellent	<input type="checkbox"/> Good	<input type="checkbox"/> Poor	<input type="checkbox"/> Very Poor	<input type="checkbox"/> Don't Know. Need more information
Comfort Care	<input type="checkbox"/> Not An Option	<input type="checkbox"/> Excellent	<input type="checkbox"/> Good	<input type="checkbox"/> Poor	<input type="checkbox"/> Very Poor	<input type="checkbox"/> Don't Know. Need more information
Gastrostomy	<input type="checkbox"/> Not An Option	<input type="checkbox"/> Excellent	<input type="checkbox"/> Good	<input type="checkbox"/> Poor	<input type="checkbox"/> Very Poor	<input type="checkbox"/> Don't Know. Need more information

For the following questions, indicate the one that best reflects your feelings.

How ready are you to make this decision?

- Very ready – my mind is made up. The decision that I have made is:

- Somewhat ready – I need more time or more information
- Not ready – I do not fully understand everything

What do you need or who do you think you need to talk to in order to help you make this decision?

What questions do you have?