# G-Tubes

#### A GUIDE TO TUBE FEEDING AT HOME

AN EDUCATIONAL ACTIVITY BOOK

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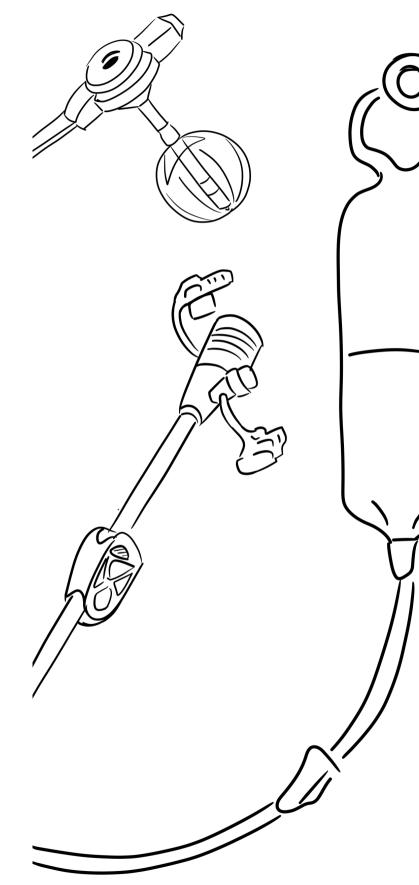
Learn more about g-tubes by following Taylor throughout her day.

#### 28 NOTE TO PARENTS

Age appropriate ways to help support your child.

#### 29 RESOURCES

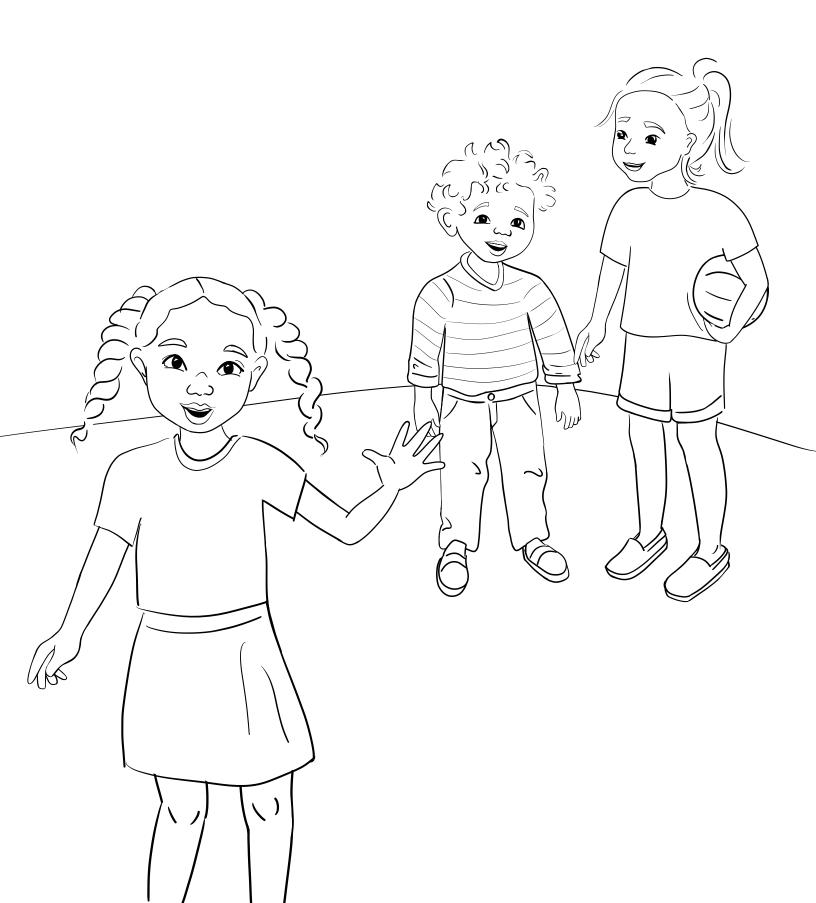
A list of tube feeding and g-tube resources for you and your child.



Hi! My name is Taylor.

I am so glad you are joining me during my day.

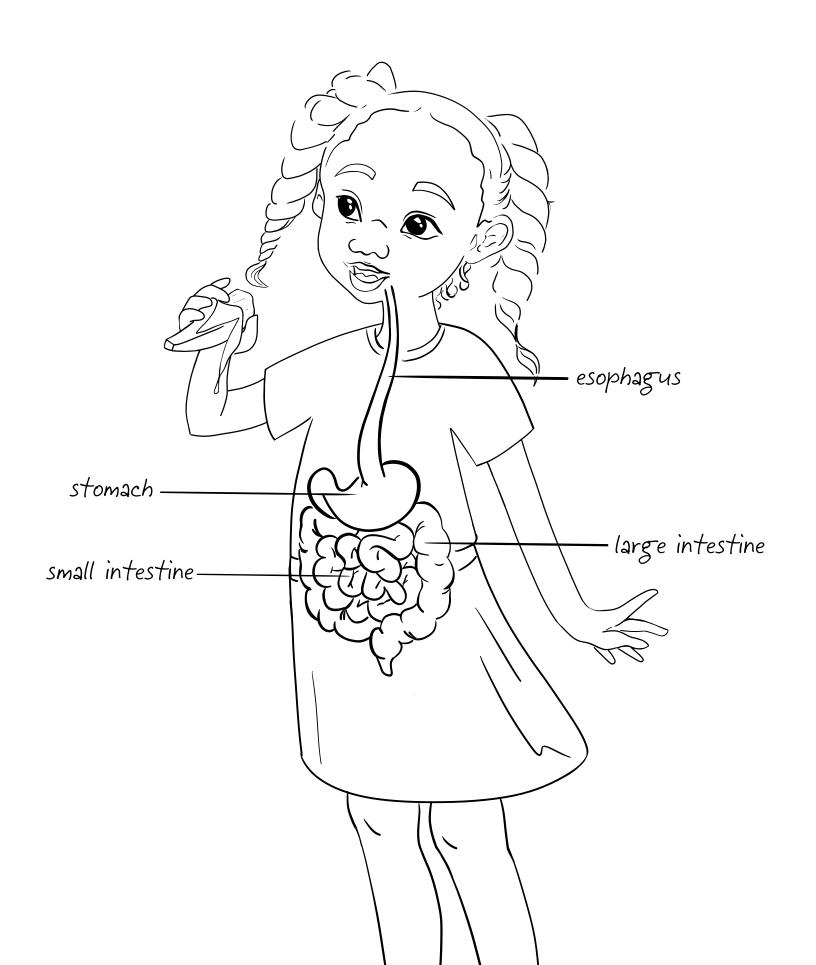
These are my friends!
We are going to start our day with a picnic at the park.



Most of my friends packed sandwiches for their picnic lunch. When my friends eat their sandwiches, the food goes down their throats and into their stomachs.

#### Do you know what your stomach does?

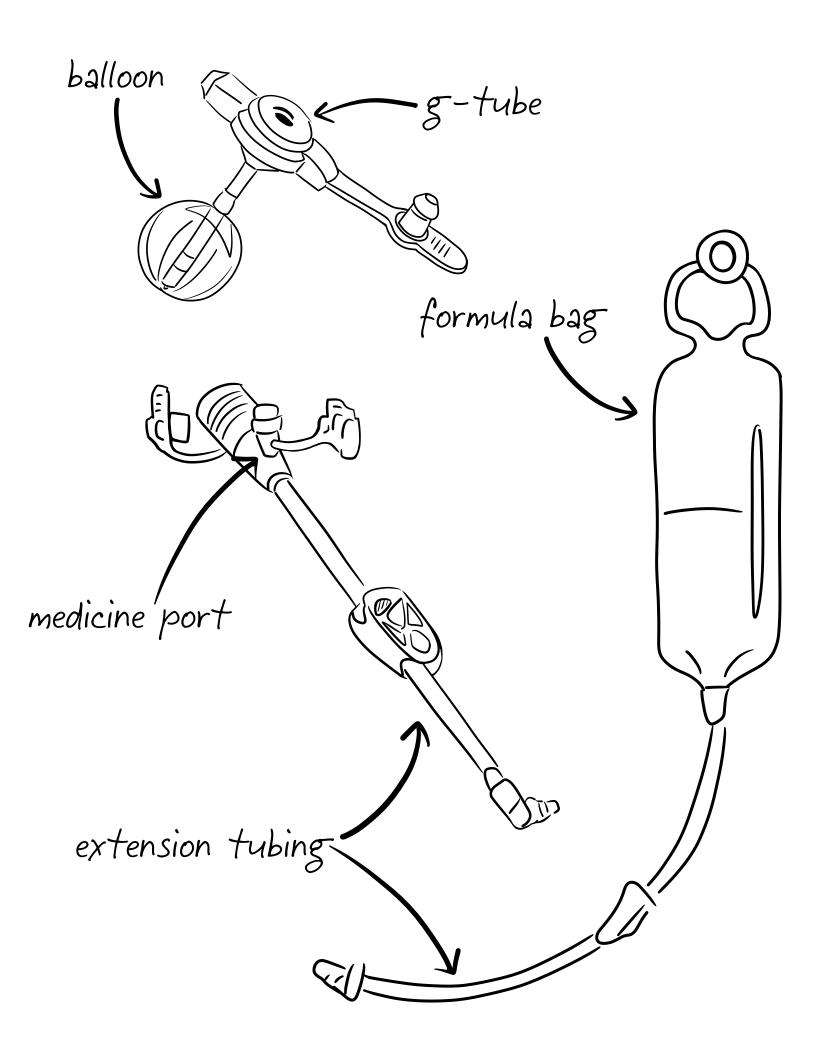
Your stomach breaks down food. Then your body uses it to help you grow and give you energy to play!



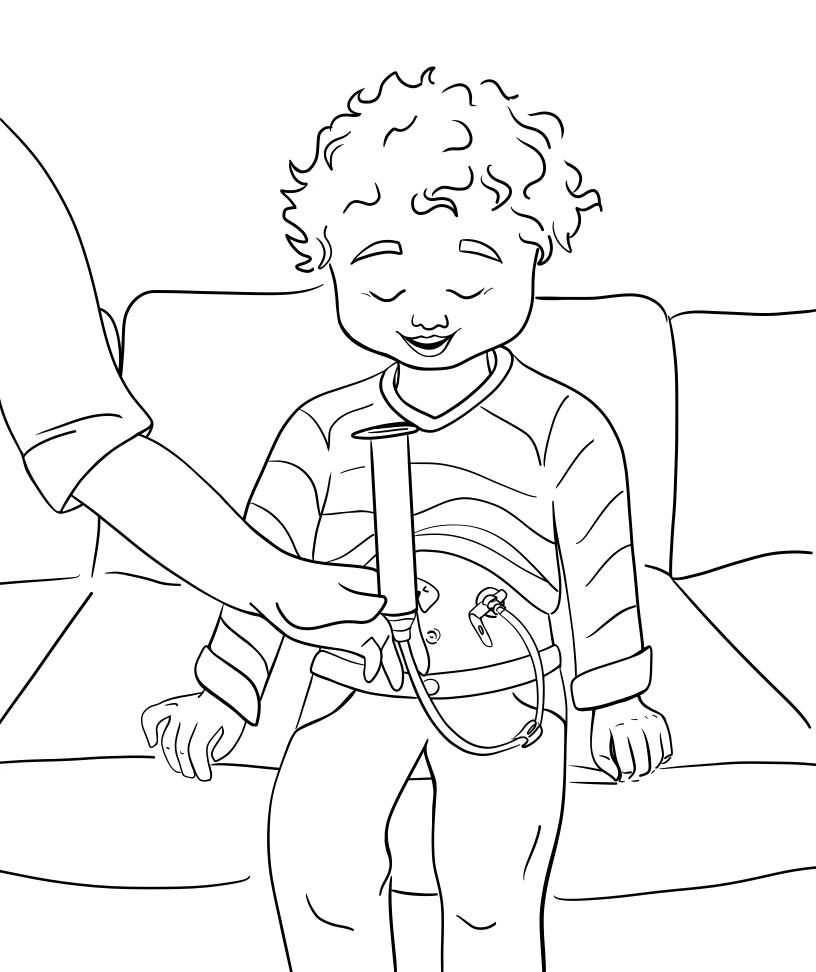
Did you know that not all kids only eat food? My friend Sam and I need something special to help us grow big and strong. Can you guess what it is?



Sam and I have feeding tubes that go into our stomachs. They are called gastrostomy tubes or gradules. I can eat solid food, but I also use my g-tube to get liquid food, called formules.



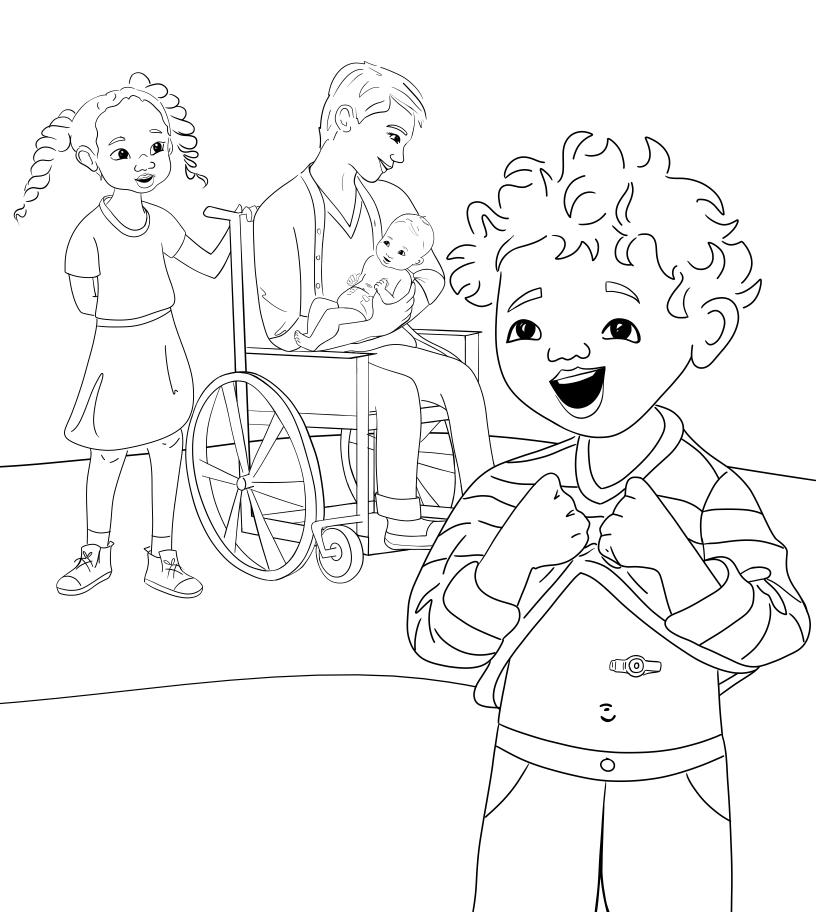
Sam cannot eat solid food like me, so he only gets formula in his g-tube. Our formula goes into our g-tubes and straight into our stomachs. It gives our bodies the extra help they need to grow big and strong!



Kids and adults of all ages can have g-tubes.

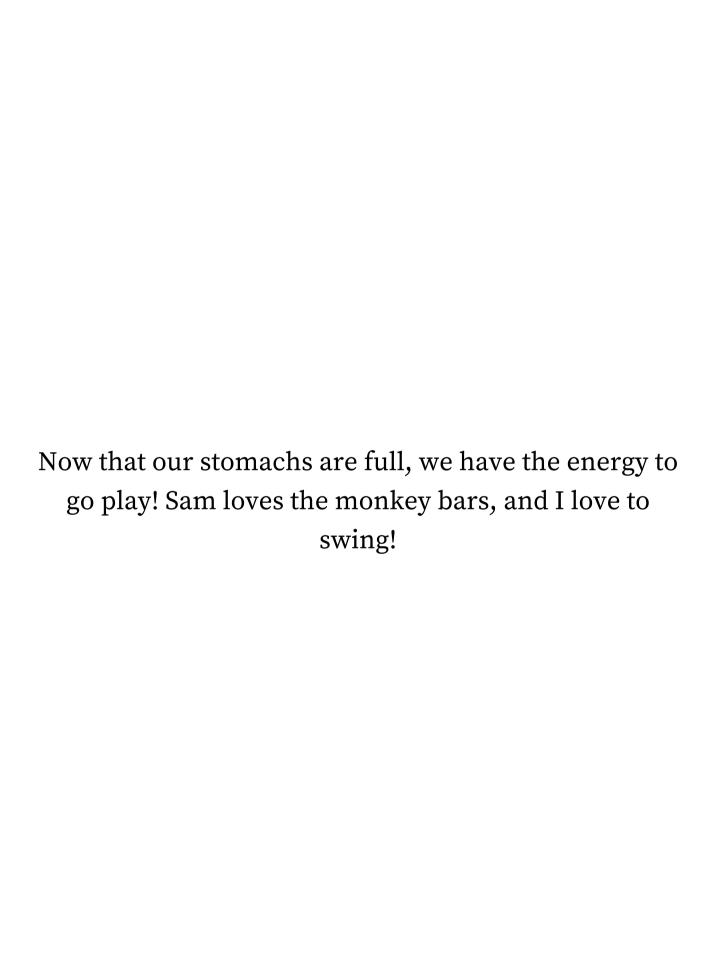
# Can you guess how many people in this picture have a g-tube?

Hint: everyone in this picture has a g-tube! You cannot always see a g-tube under your clothes.



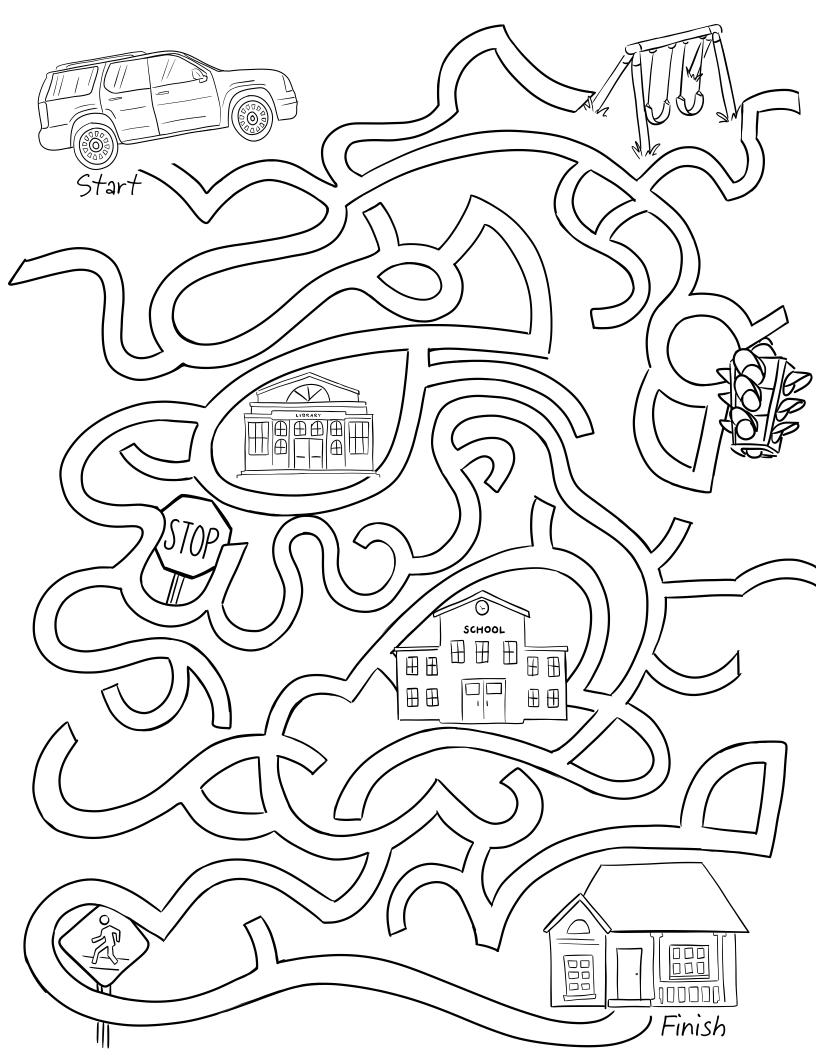
_	m and I have g-tubes, v with all of our friends!	ve can still play
Can you find all	of the things that we lov	e to play with?
Slide	Monkey Bars	Ball



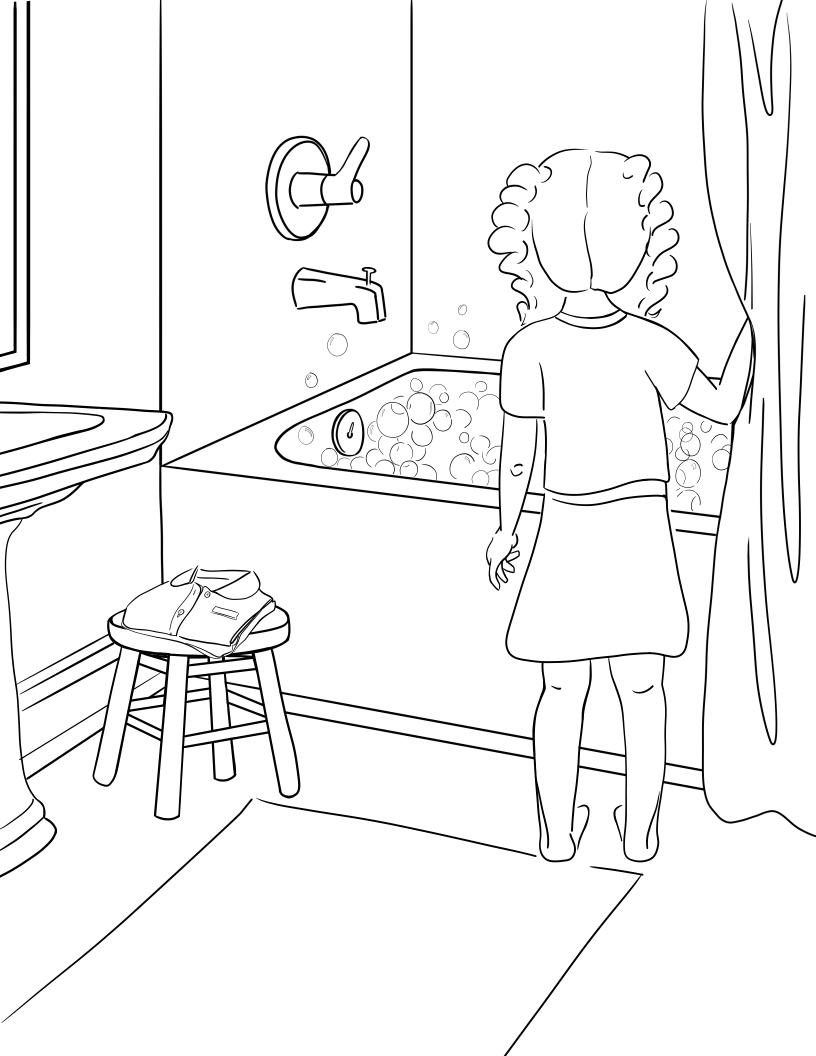




Playing at the park with my friends was so much fun! Now it is time to head home and get ready for bed. Can you help me get home?



The first thing I do when I get home is to Then, I put on my pajamas and brush	



Now it is time to clean around my g-tube.

I always wash my hands before touching around the site where my g-tube is. This helps it to not get sore or infected with germs.



Now it is time for bed! I like to read a story before going to sleep.

What do you like to do before bed?

Thank you for spending my day with me! Goodnight.



### **NOTE TO PARENTS**

Below you will find tips and tricks for children of different ages who have a g-tube. You can also use these tips and tricks for any siblings that your child might have. It is important to remember that every child is unique. Your child might not fit exactly into their age group shown here, and that is okay! You know your child best. Find where you think they fit best and follow those tips.

#### Ages 0-1 year old:

- -Dress your child in a onesie to keep your child from pulling at their tube.
- -Allow your child to continue to do "normal" things (tummy time, play time, etc.).
- -Focus on continuing to bond with your child by holding during feeding time when able, snuggling with your child, and responding to your child when he or she cries.

#### Ages 2-4 years old:

- -Provide your child with opportunities for control and independence when possible. (opening the button when time for feeds, choosing where to get their feeds, selecting their outfit, etc.).
- -Praise your child when they complete a task well and independently.
- -If your child fails at something they have tried to do on their own, try not to criticize them. Instead, help them finish it to encourage a sense of accomplishment.
- -Allow and encourage your child to ask questions about the world around them and particularly about their g-tube and medical care.

#### Ages 5-10 years old:

- Provide your child with an appropriate job to do (opening the button when time for feeds, mixing formula, cleaning the site, etc.).
- -Allow your child to continue to play with their peers and siblings, whether the other children have medical needs like your child or not.
- Encourage your child to find things that they are good at and help them to work on these things (art, sports, reading/writing, etc.).

#### Ages 11+ years old:

- -Allow your child to increasingly become more involved in their own care.
- -Provide your child privacy as appropriate.
- -Encourage your child to continue to grow their friendships.
- -Your child is starting to figure out what their identity will be and will have to figure out how having a g-tube fits into their identity. Continue to be there for your child as they navigate this tough transition and think about how they see themselves fitting into society (work opportunities, educational opportunities, etc.).

# **RESOURCES**

Below are some resources that are helpful for parents or caregivers of children with g-tubes.

#### **Tubie Friends**

tubiefriends.com

This organization offers stuffed animals with g-tubes in them for children who have g-tubes. Sibling stuffed animals are also offered for purchase.

#### **Feeding Tube Awareness Foundation**

feedingtubeawareness.org

This organization has resources and educational information that many parents and caregivers have found helpful. This organization also has a Facebook page for further support.

#### **Oley Foundation**

oley.org

This organization works to provide education, advocacy, and networking to both adults and children who engage in tube feeding. The organization has a number of resources for parents and caregivers, in addition to providing a program for connecting individuals with unused g-tube supplies to individuals with a need for those g-tube supplies.

#### When Jeremy Jones' Stomach Stopped Working

This book is a great story book of a young boy who has to get a g-tube.

A printable copy can be found at:

mitoaction.org/wp-content/uploads/2019/09/Jeremy-Jones-GTube-Book.pdf