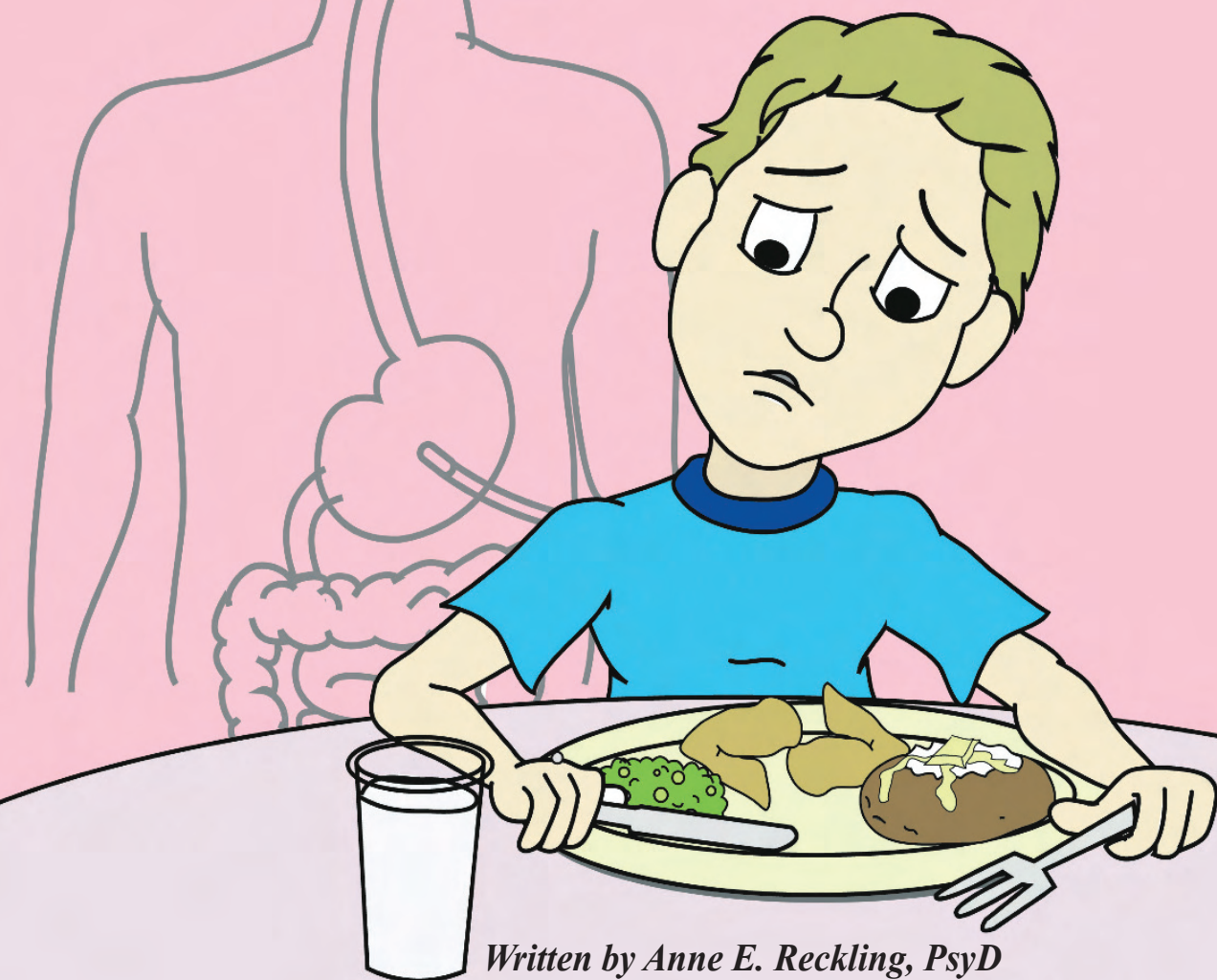


When Jeremy Jones' Stomach Stopped Working

*A Story for Children
With G-Tubes*



Written by Anne E. Reckling, PsyD

Illustrated by Tim O'Halloran

A Note to Parents and Professionals:

When Jeremy Jones' Stomach Stopped Working: A Story For Children With G-Tubes is intended for children from preschool to middle school who either have or need a g-tube (i.e. a gastrostomy tube for feeding) or have a sibling or friend with a g-tube. It is intended to help children with g-tubes recognize their strengths, understand more about their g-tubes and g-tube surgery, and accept their g-tubes as an important part of their growth and continuing strength. In addition, humor is used to capture the reader's imagination and help keep a sense of 'lightness' about the subject while still explaining the medical facts.

Please read this book with your child and then open the door for your child to talk with you by asking questions. You can start by asking your child how he or she thinks Jeremy feels and thinks: What does Jeremy worry about? What does he feel good about? What happens once he gets the g-tube? Questions about Jeremy's thoughts and feelings will give your child an opportunity to express thoughts and feelings that he or she might not otherwise feel comfortable speaking about. If your child is reluctant to talk, that is okay. You can let your child know that you are available to talk anytime.



This book was funded and produced in cooperation with the Mitochondrial Disease Action Committee. MitoAction is a nonprofit organization dedicated to improving the daily quality of life for patients and families affected by Mitochondrial Disease.

Support projects like this book and learn more about mitochondrial disease by visiting us at www.mitoaction.org

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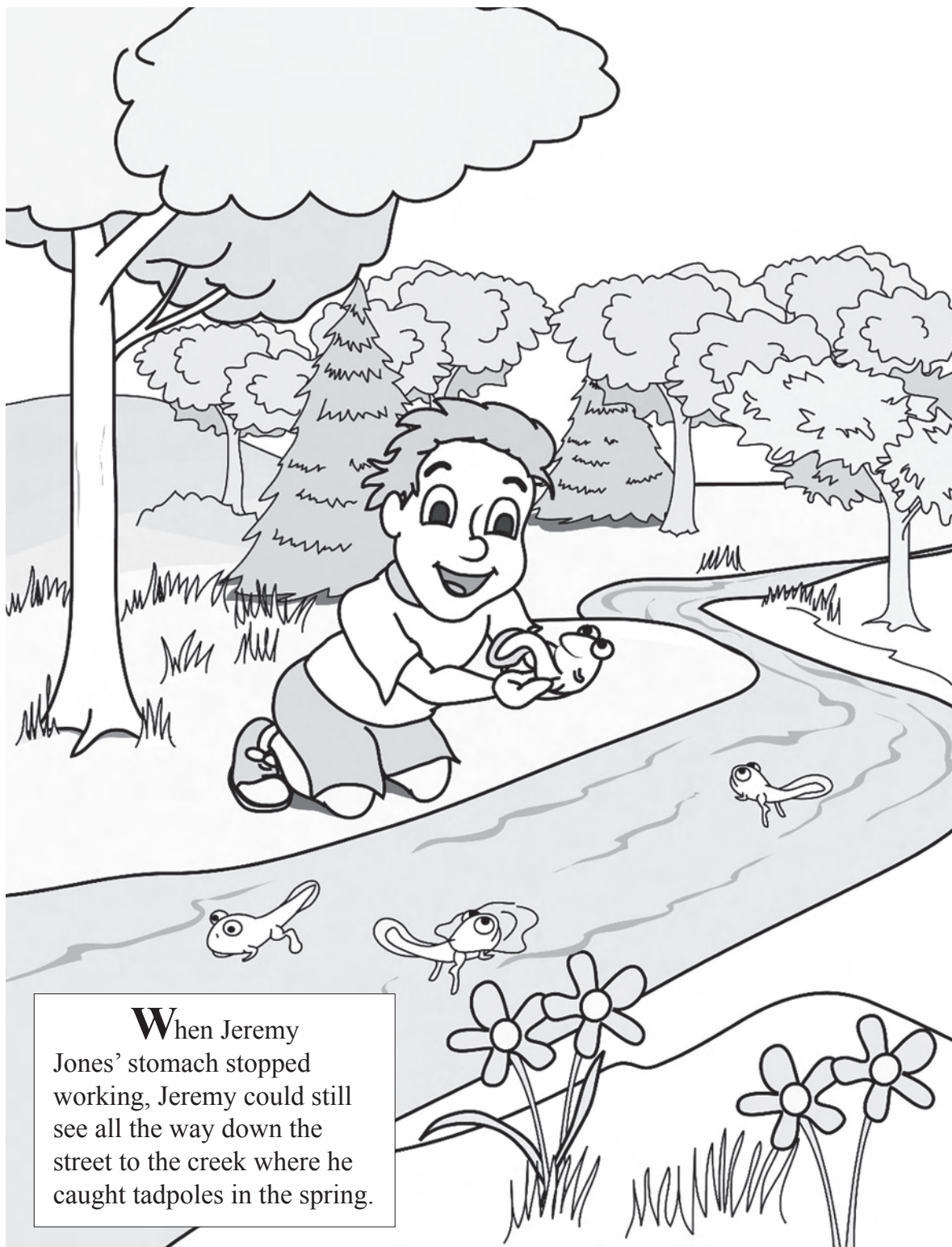
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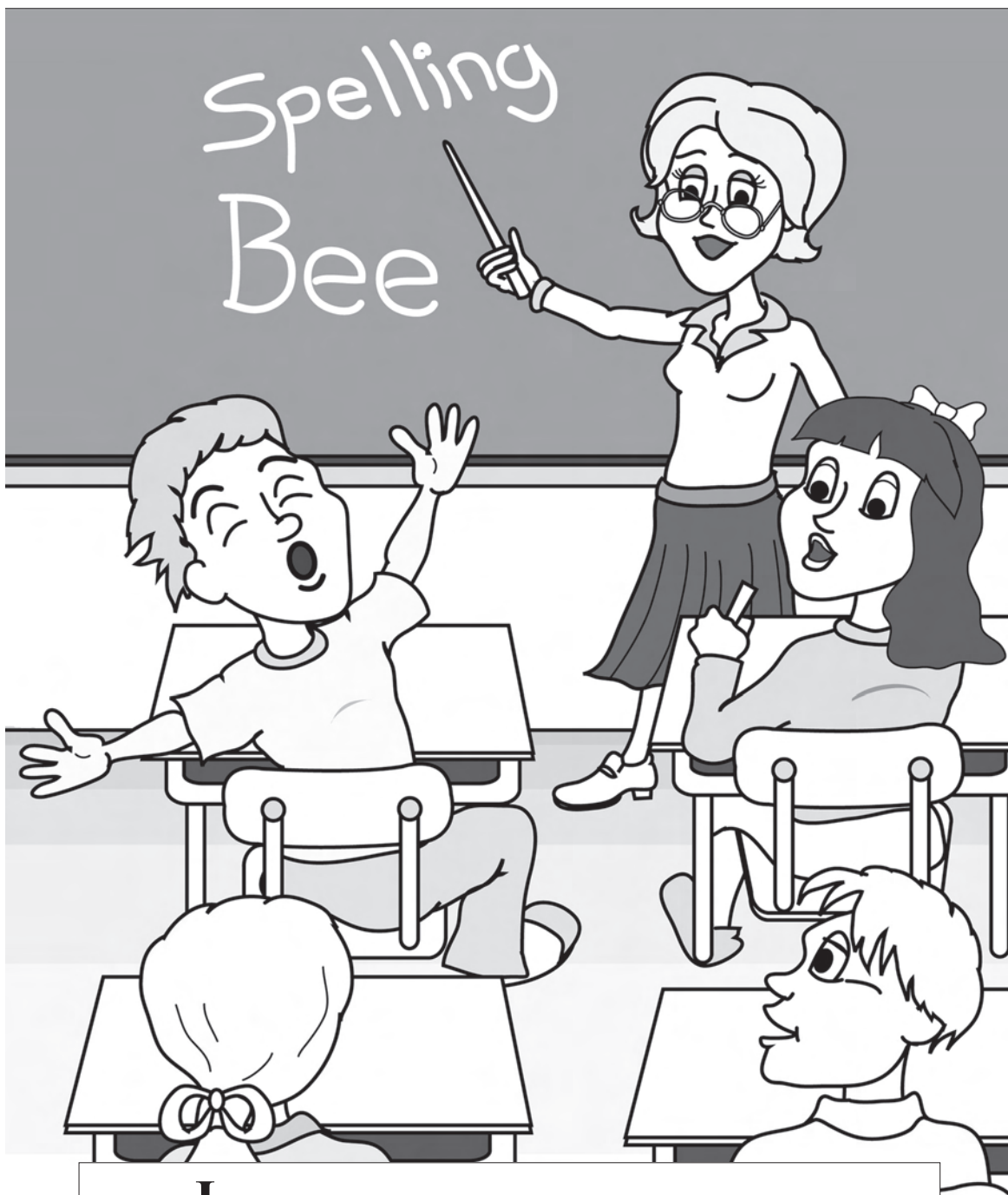


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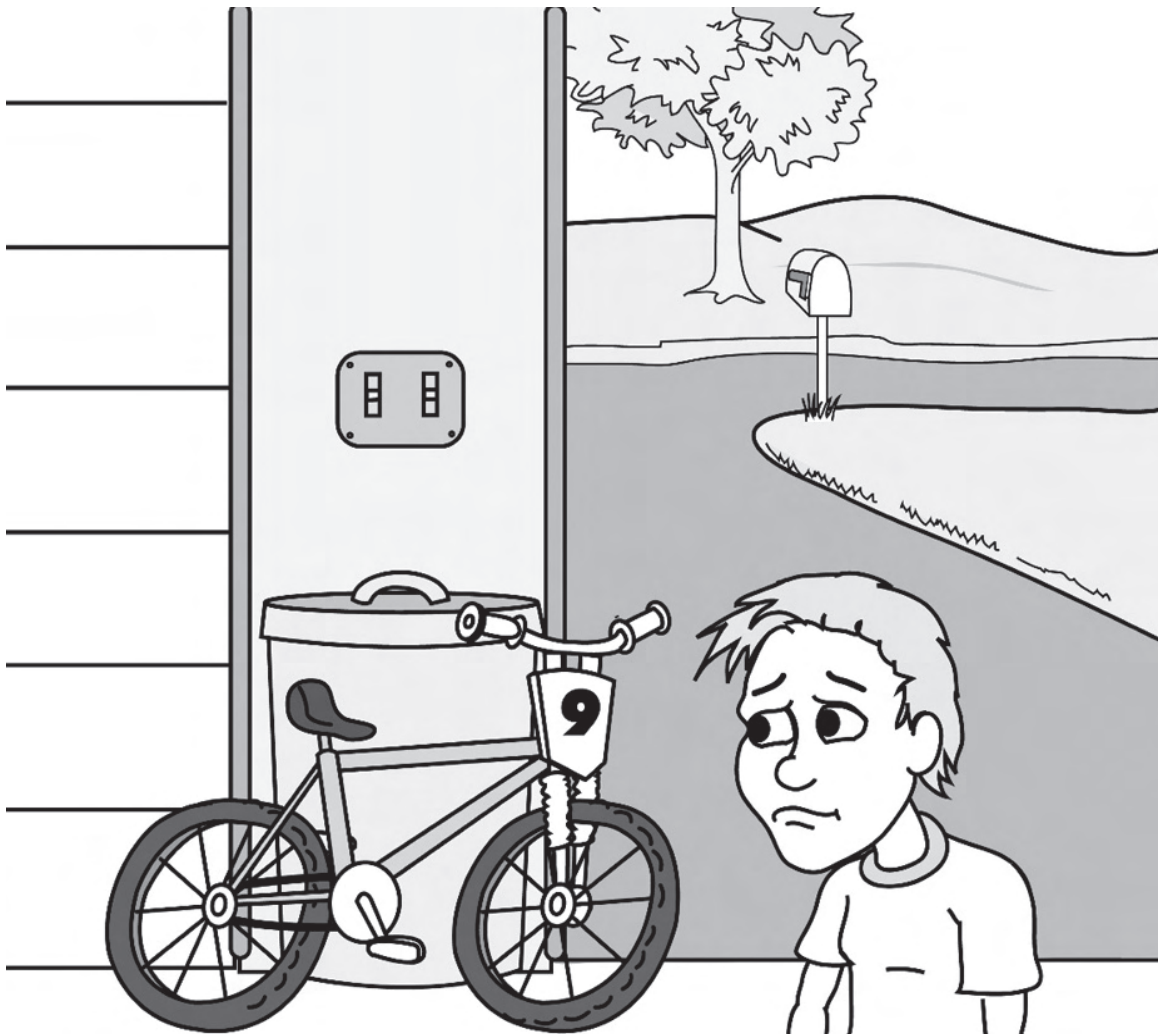
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When Jeremy Jones' stomach stopped working, Jeremy could still see all the way down the street to the creek where he caught tadpoles in the spring.

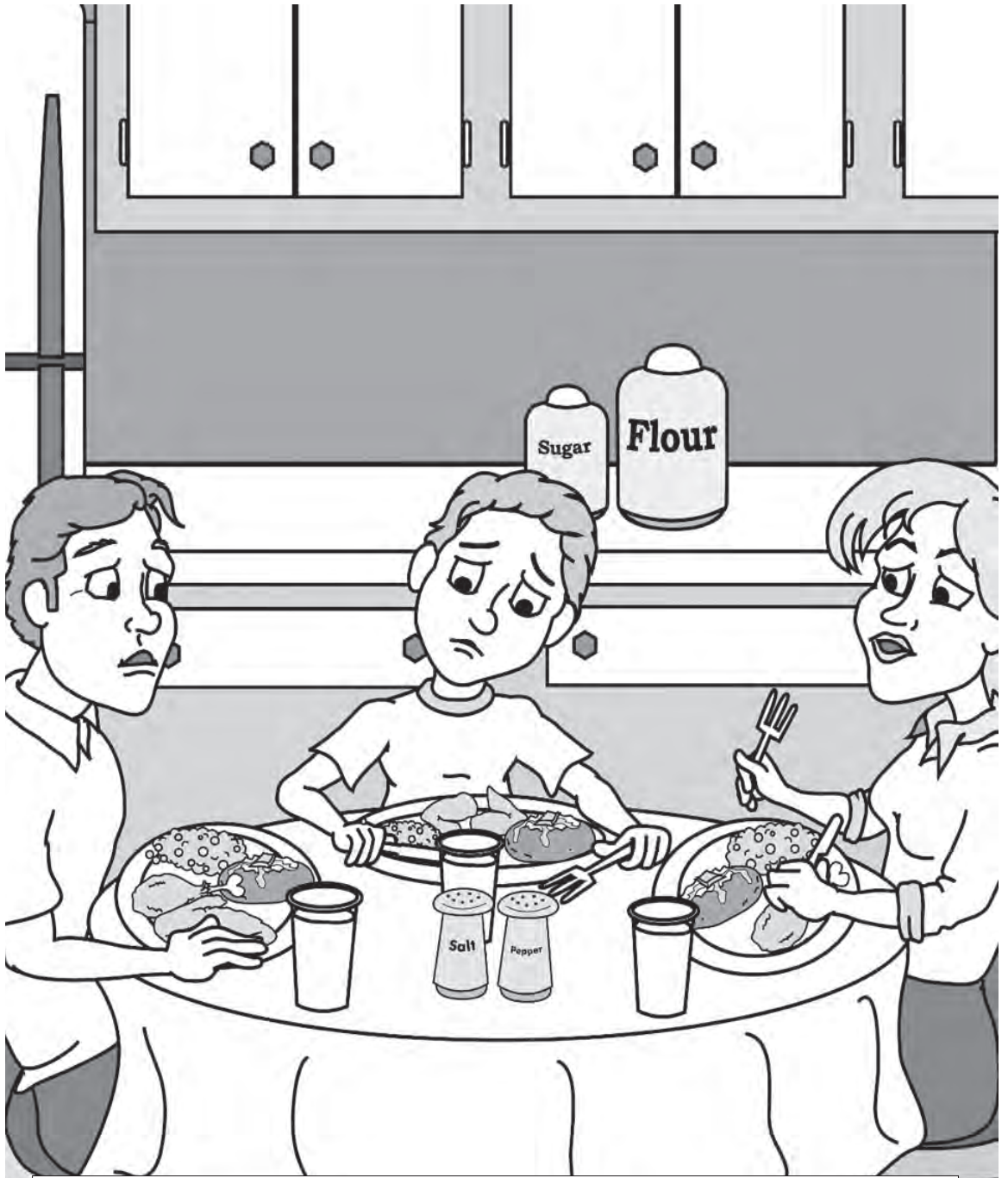


Jeremy's voice still rang out loud and clear so that his music teacher said "Bravo!" when he sang and his classroom teacher said "Hush, Jeremy!" when he sang by mistake during spelling tests.



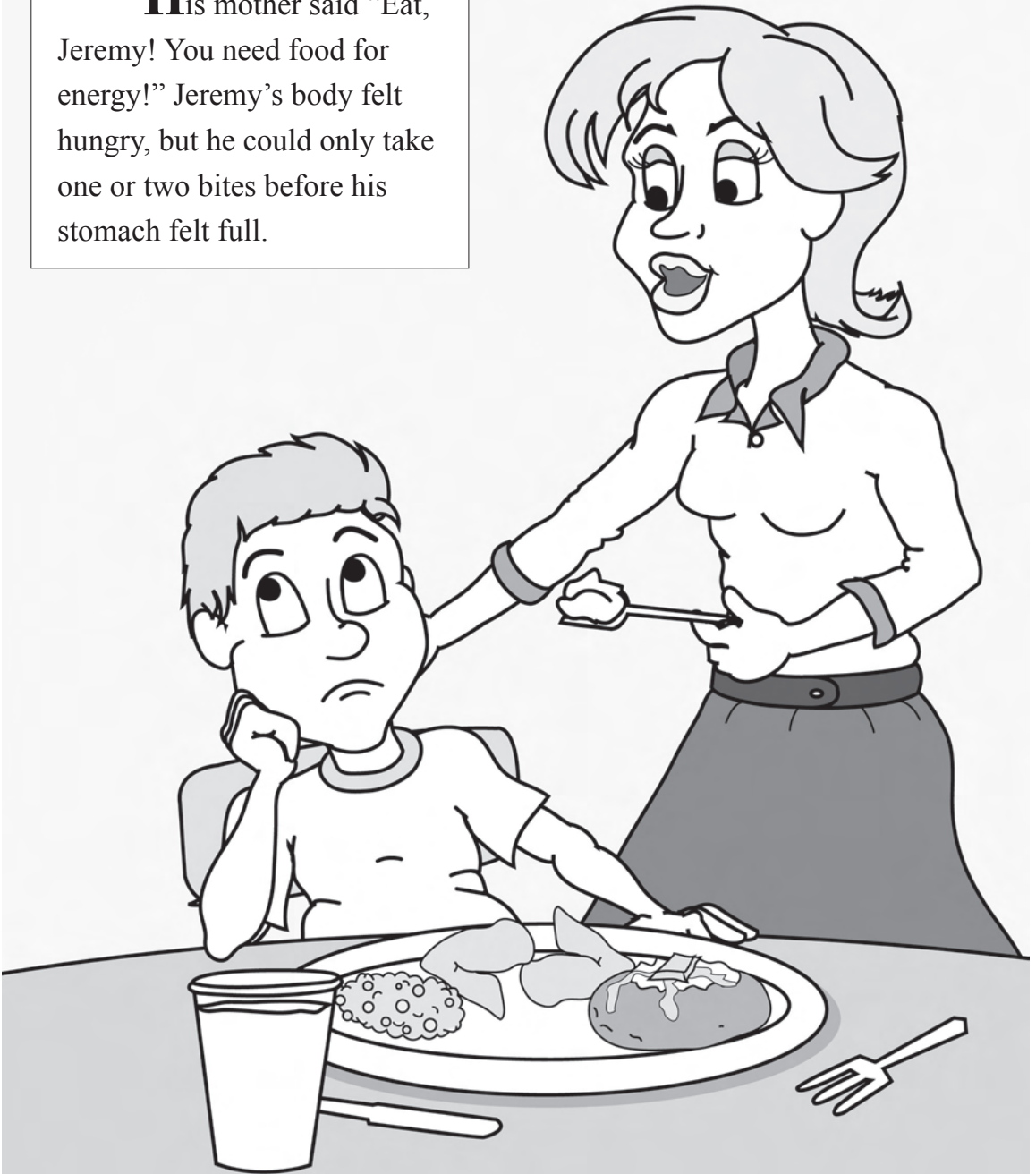
When Jeremy's stomach stopped working, Jeremy's legs could still pump his bike pedals and his arms could climb the ladder to his tree house, but Jeremy was too tired to ride and too hungry to climb.





Jeremy's stomach stopped working a little bit at a time so that no one, not even his mother and dad, knew at first why Jeremy stopped eating.

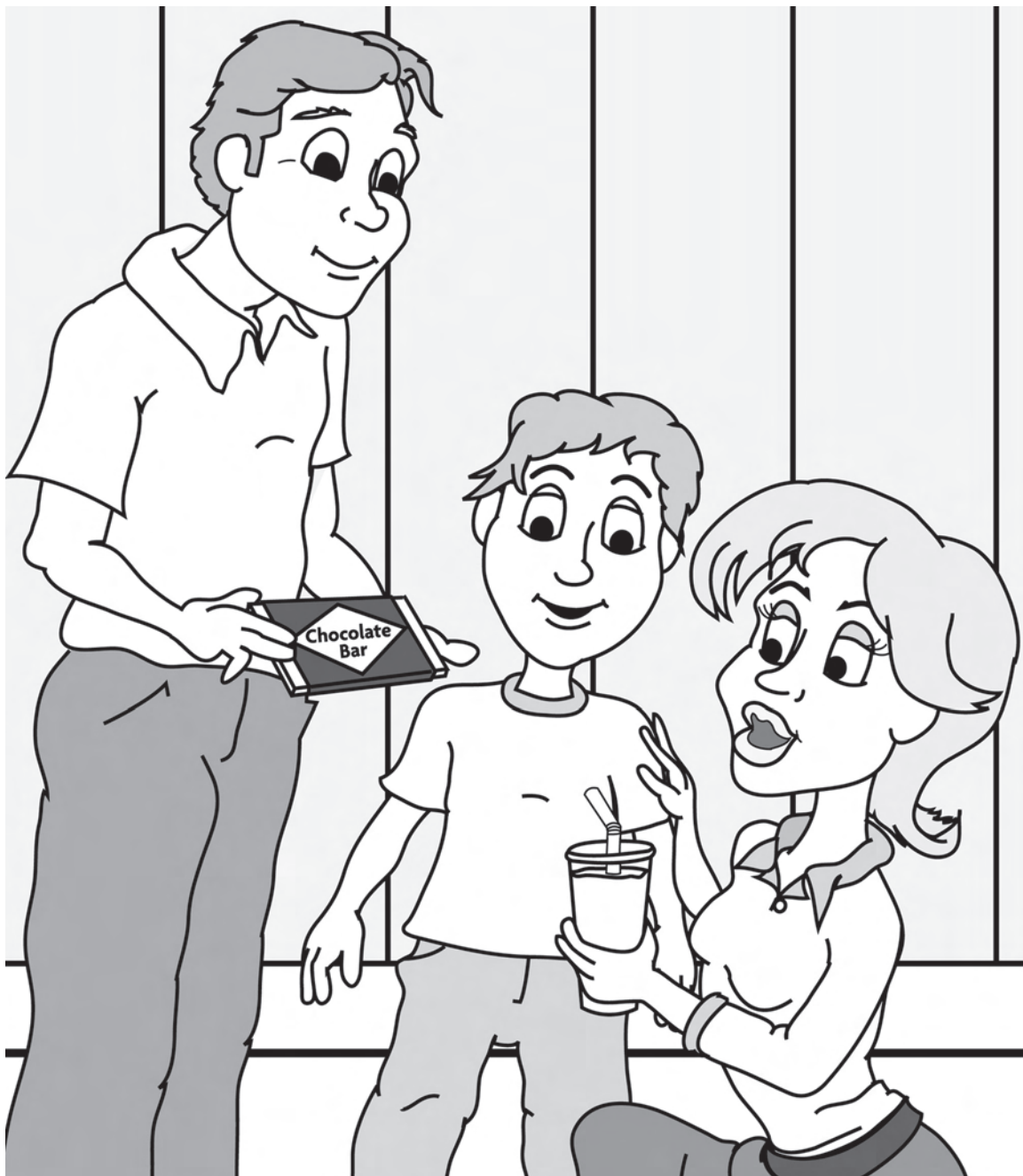
His mother said “Eat, Jeremy! You need food for energy!” Jeremy’s body felt hungry, but he could only take one or two bites before his stomach felt full.



His father said, “Eat, Jeremy! You can’t leave the table until you eat your dinner!”

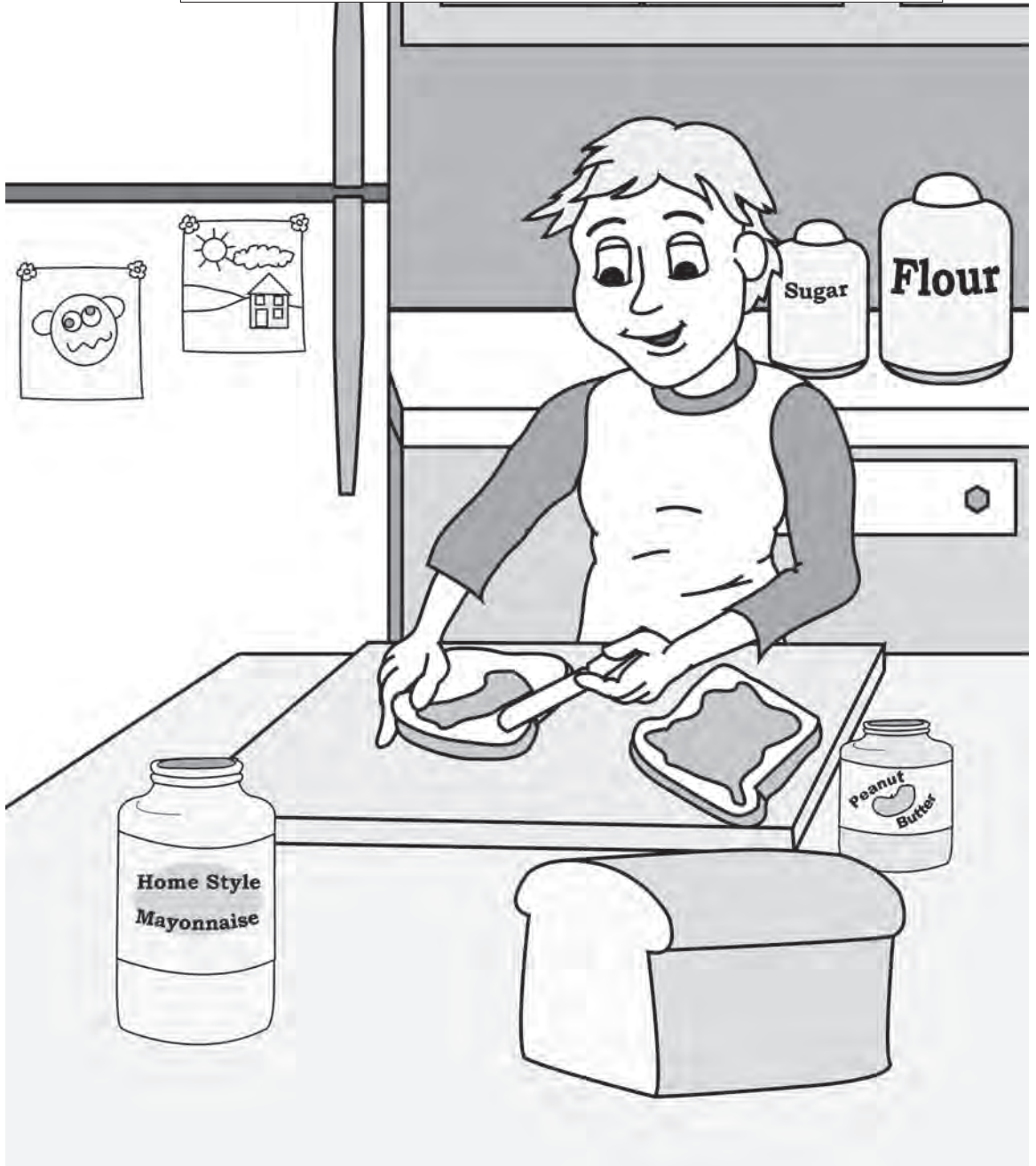


Jeremy took three bites of mashed potatoes, one bite of peas and one bite of chicken. “My stomach is going to burst!” cried Jeremy. Sometimes, he threw up.

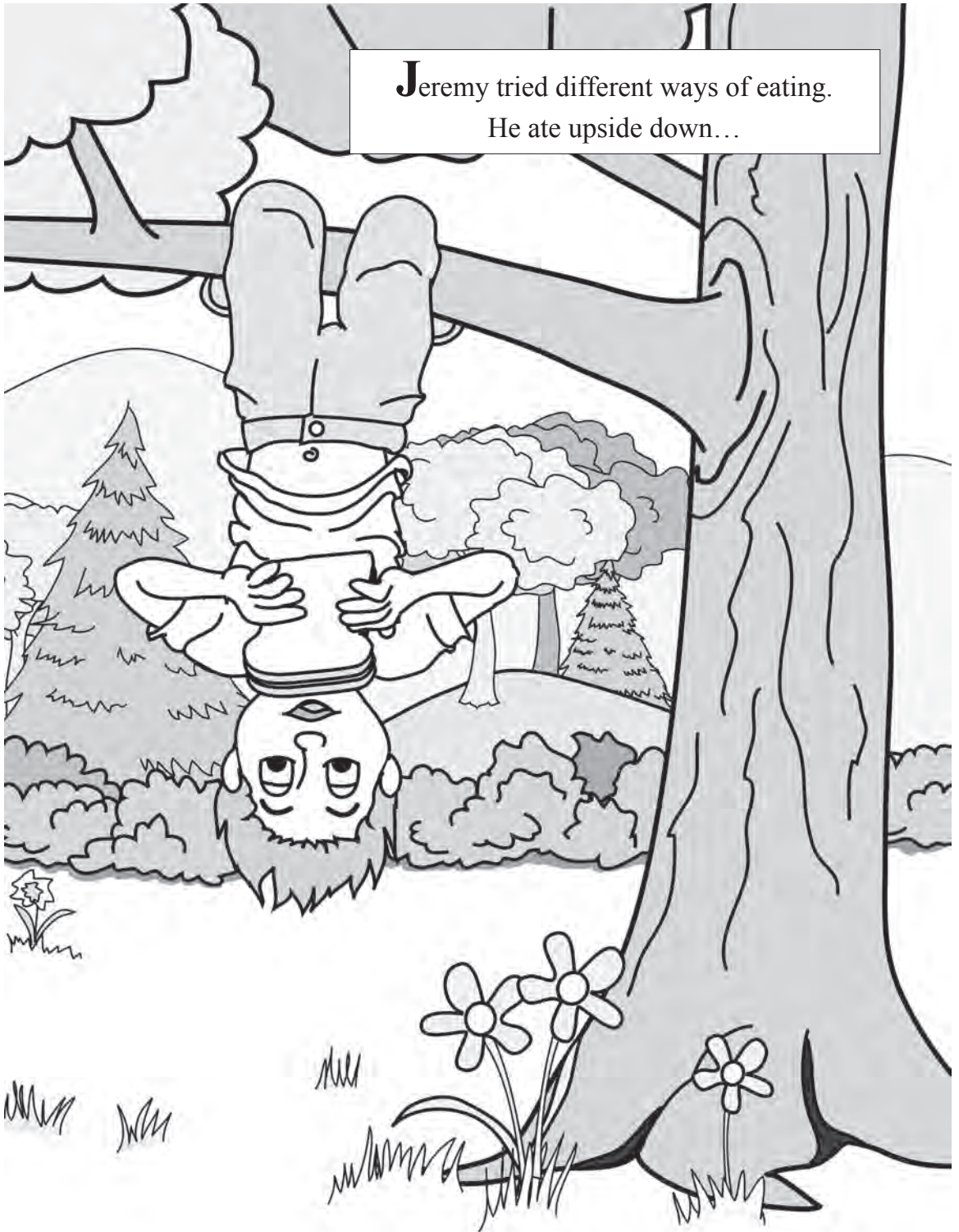


Jeremy tried different kinds of food. He tried soft food and hard food, crisp food and soggy food, sweet food and salty food. His mother made him milk shakes and his father brought him chocolate in shiny foil wrappers.

Jeremy's brother, Tim, even made Jeremy his favorite peanut butter and mayonnaise sandwiches. Jeremy took two delicious bites and sadly said, "I'm full!"



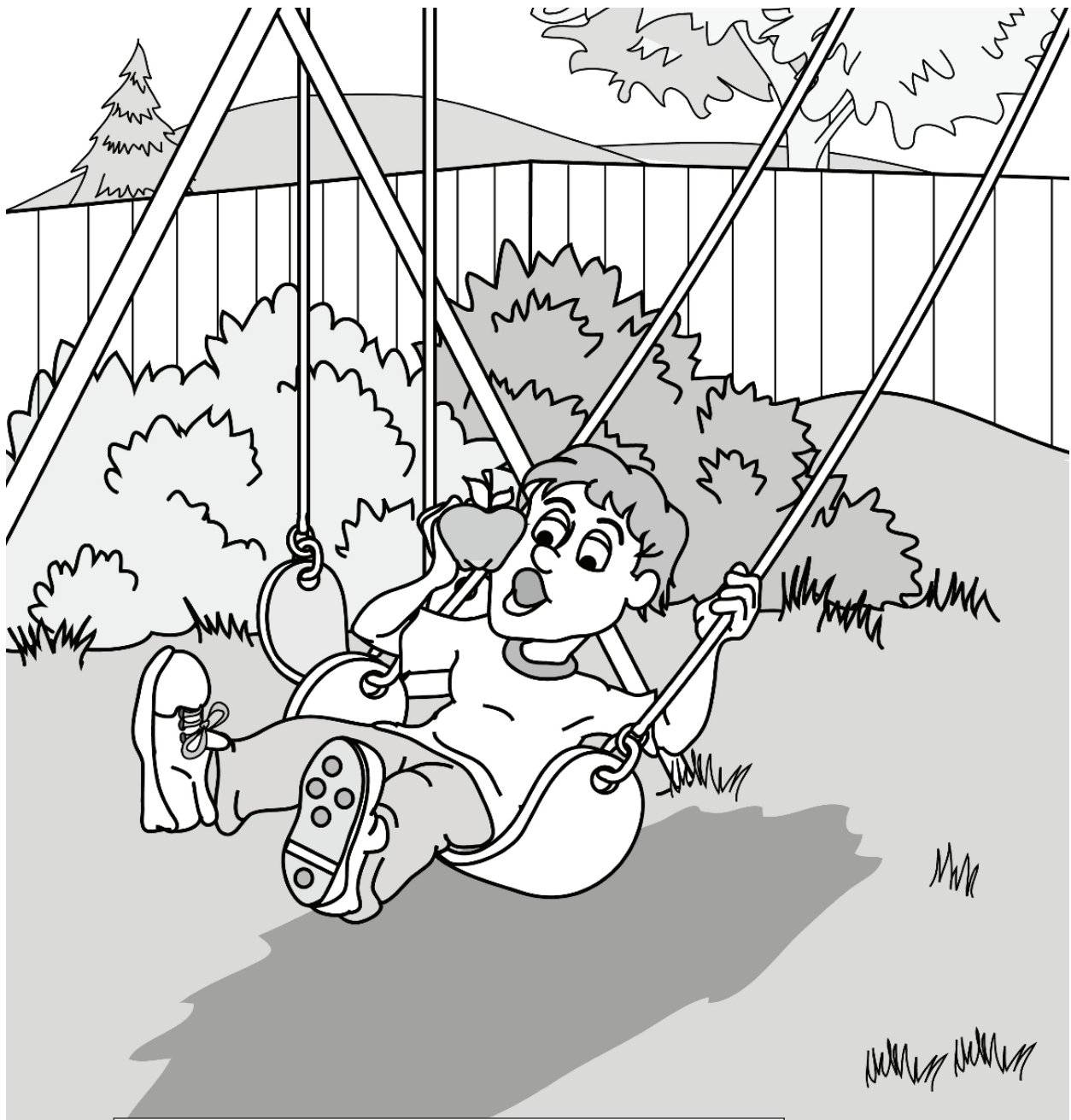
Jeremy tried different ways of eating.
He ate upside down...







He ate in a car and in a tree and ...



.... on a swing and in his room and at the house of his best friend, Roger. But his stomach still felt so full it hurt after two bites and his body still felt hungry.

Jeremy's mother and father took him to the doctor.

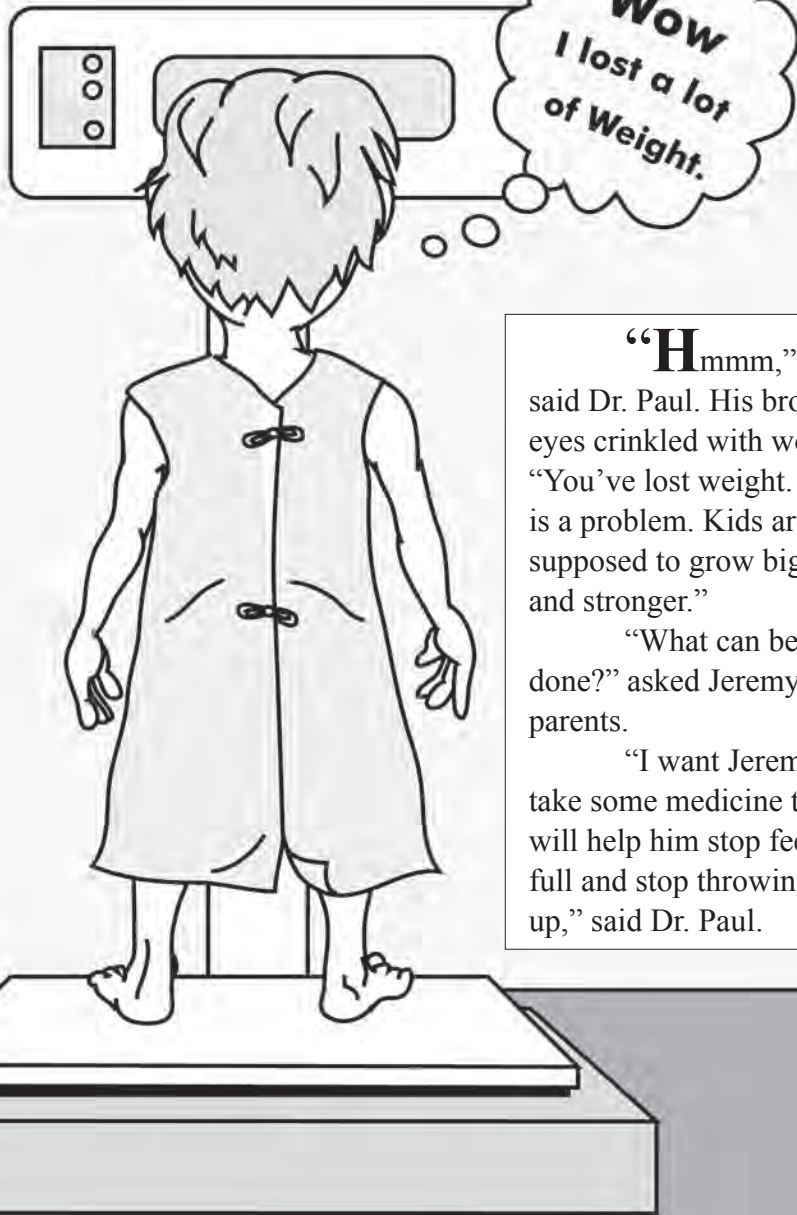
"It hurts to eat! I feel so full after only a few bites. Sometimes, I throw up," Jeremy told Dr. Paul.



“What have you been eating?” asked Dr. Paul.

“I’ve tried everything I can. I’ve had soft food and hard food, crisp food and soggy food, sweet food and salty food. Milk shakes, chocolate in foil wrappers, and peanut butter and mayonnaise sandwiches. I’ve eaten upside down and sideways. I’ve eaten in a car, a tree, my room, my friend’s house, and, of course, in the kitchen. But, nothing has worked. I still feel full after two bites and my stomach hurts,” answered Jeremy.

The doctor had Jeremy stand on the scale.



“**H**mmm,” said Dr. Paul. His brown eyes crinkled with worry. “You’ve lost weight. That is a problem. Kids are supposed to grow bigger and stronger.”

“What can be done?” asked Jeremy’s parents.

“I want Jeremy to take some medicine that will help him stop feeling full and stop throwing up,” said Dr. Paul.

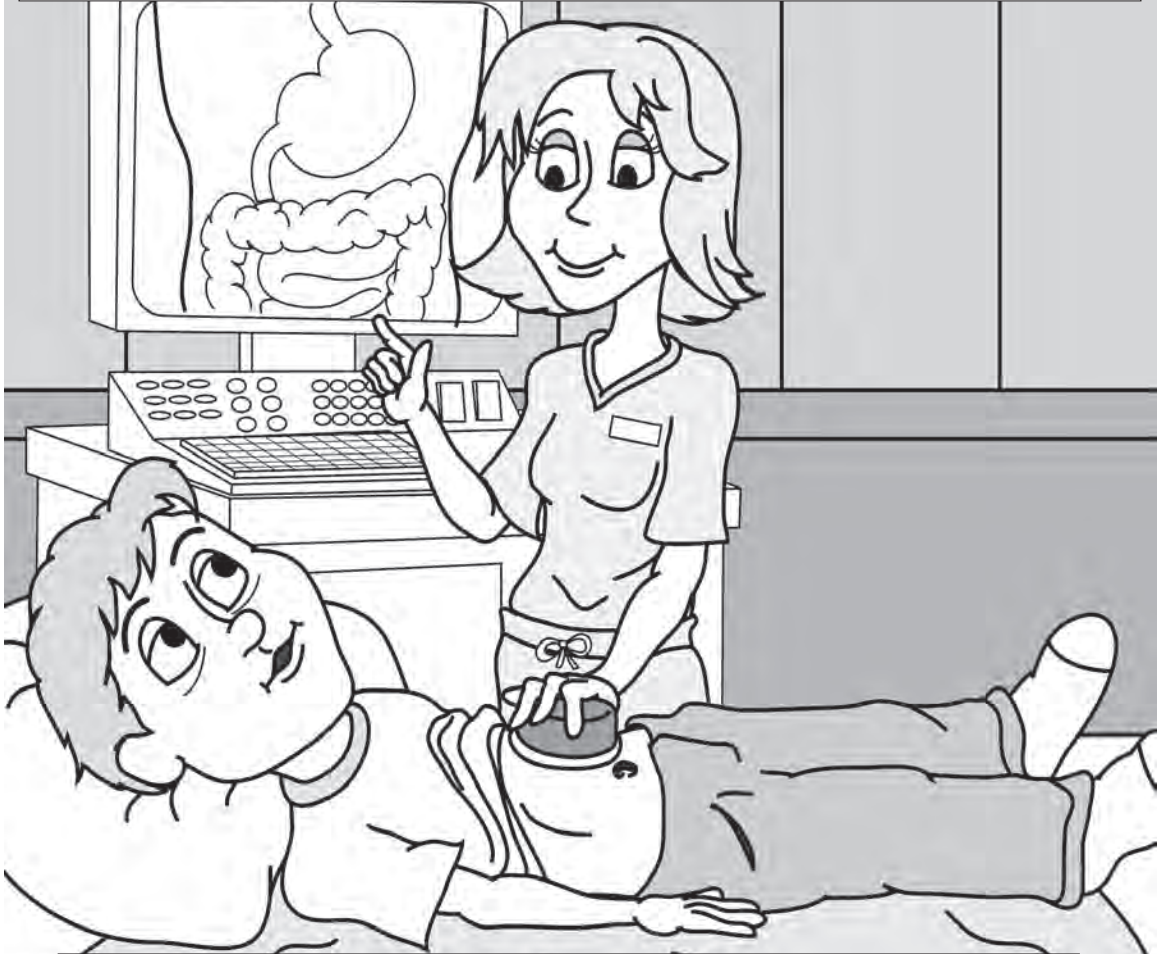


Jeremy took the medicine twice a day,
but he still could not eat more than two bites.
“I’m so hungry and tired,” said Jeremy sadly.



Jeremy went back to Dr. Paul's office. Dr. Paul peered over his glasses and looked at Jeremy and his parents. "I will have to run some tests on Jeremy's stomach. We have to know why he can't eat."

Jeremy's doctor did some tests on Jeremy's throat, stomach, and intestines. In one test called a gastric emptying scan, he ate some oatmeal with a special dye inside. It didn't taste bad and it didn't hurt. The doctors took pictures of how fast the oatmeal left his stomach. Jeremy thought the oatmeal seemed to take a really long time to leave his stomach and enter his intestines! In another test, he drank some white paste that tasted yucky and then sat under a special camera so the doctors could see Jeremy's stomach and intestines. Jeremy didn't mind the taste too much because the test didn't hurt and he got to see the pictures.

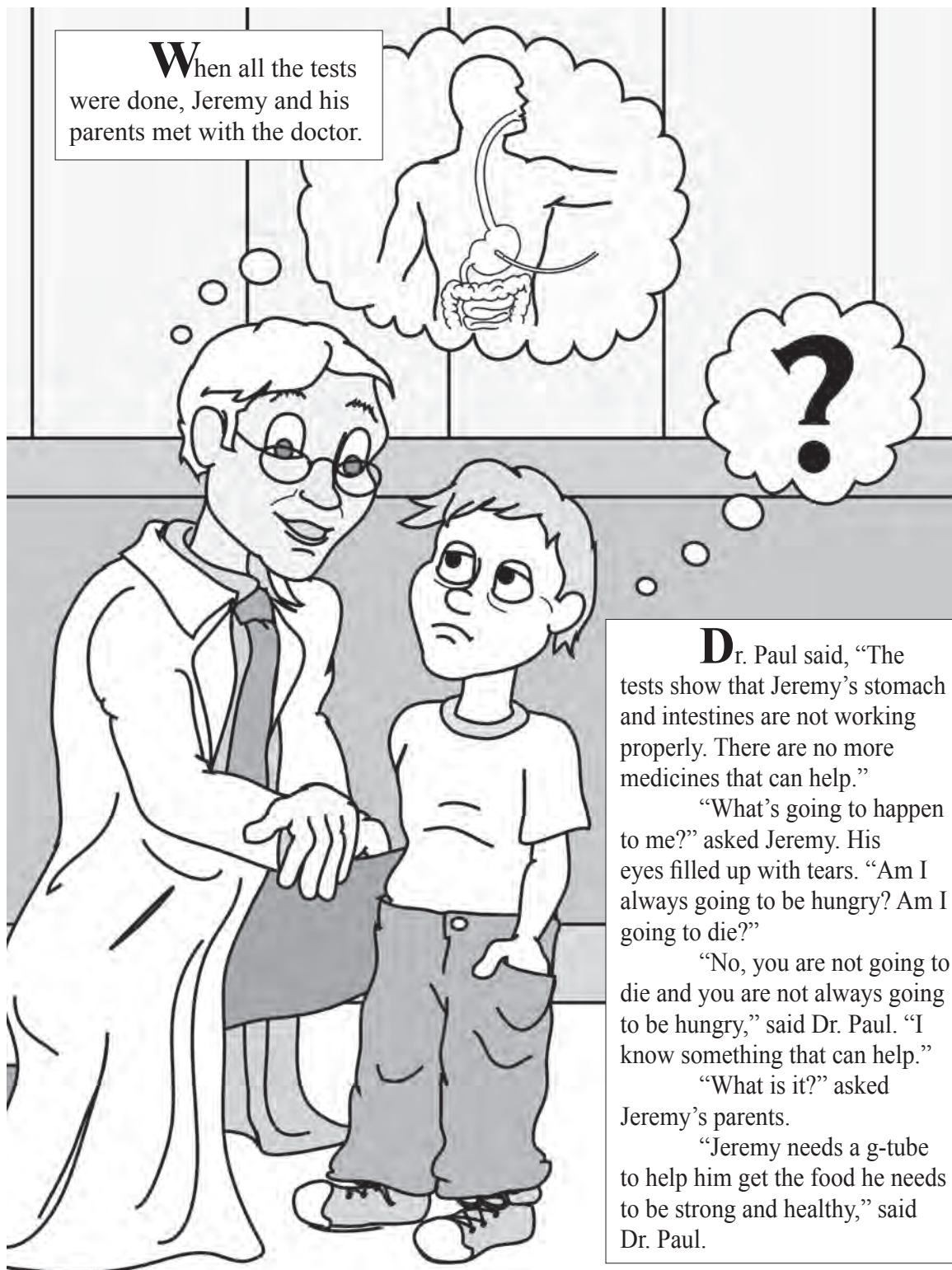


“Hey, those pictures look cool! Can I take them home with me?” asked Jeremy.

“Sure! I’ll make some copies for you,” said the nurse.

When Jeremy got home, he showed the pictures to Roger who said his intestines looked like his pet snake, Alfred. Jeremy’s brother thought they looked like spaghetti and wanted to take them to school for science class.

When all the tests were done, Jeremy and his parents met with the doctor.



Dr. Paul said, “The tests show that Jeremy’s stomach and intestines are not working properly. There are no more medicines that can help.”

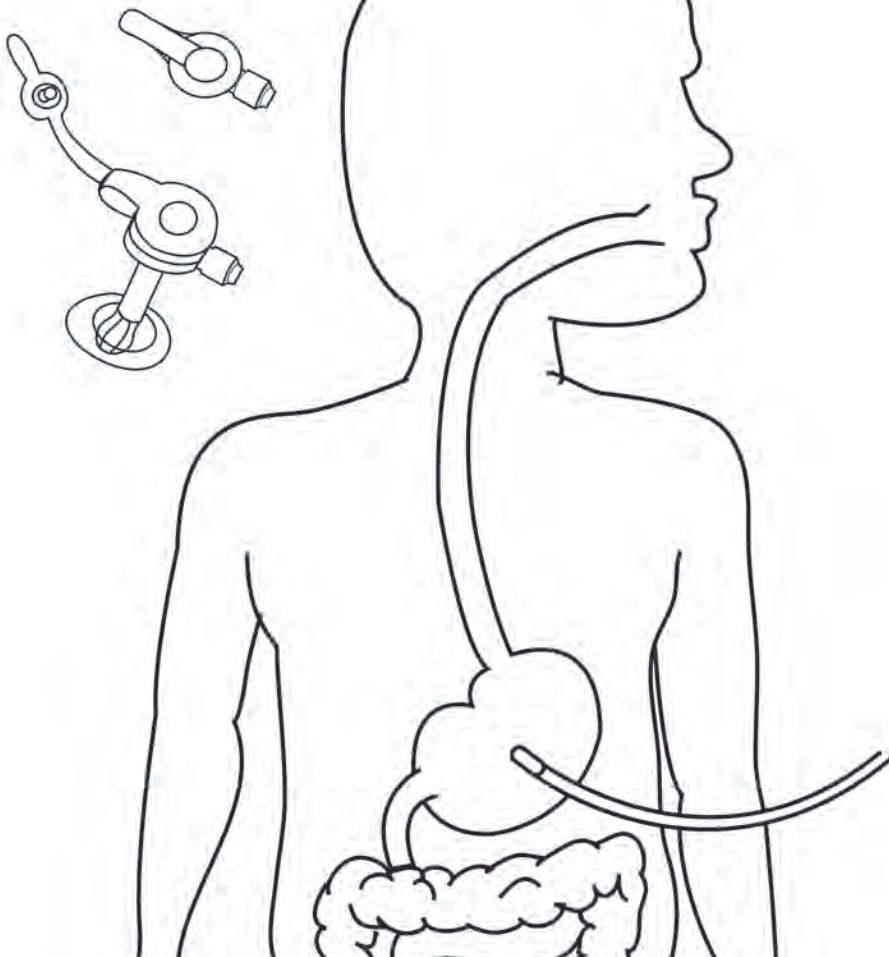
“What’s going to happen to me?” asked Jeremy. His eyes filled up with tears. “Am I always going to be hungry? Am I going to die?”

“No, you are not going to die and you are not always going to be hungry,” said Dr. Paul. “I know something that can help.”

“What is it?” asked Jeremy’s parents.

“Jeremy needs a g-tube to help him get the food he needs to be strong and healthy,” said Dr. Paul.

“What’s a g-tube?” asked Jeremy.



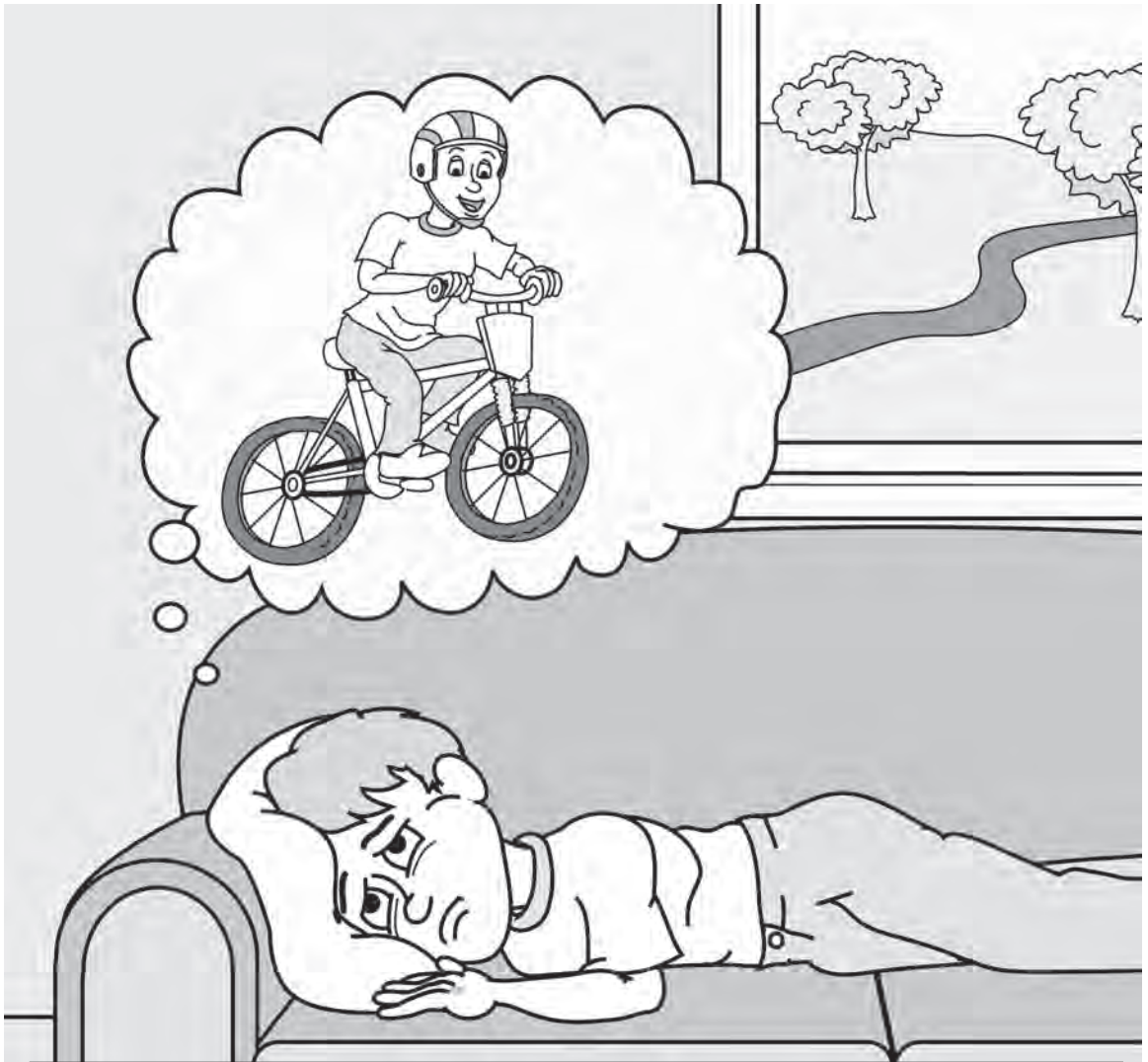
“A g-tube is a small tube that will go into your stomach. It looks a little bit like a drinking straw. The g-tube is hooked to a pump and a bag of special liquid food called formula. The formula goes through the tube and into the stomach. The g-tube and special formula will help you get the food you need without feeling sick,” explained Dr. Paul.

“Will Jeremy still be able to eat food with his mouth?” asked his parents.

“Yes, if he wants to,” answered Dr. Paul.

“But what if I feel too full or throw up when I eat with my mouth?” asked Jeremy.

“If you feel too full, you don’t have to eat with your mouth. You won’t have to worry anymore about getting enough food to grow and play because your g-tube will help you get all the food you need,” replied Dr. Paul.



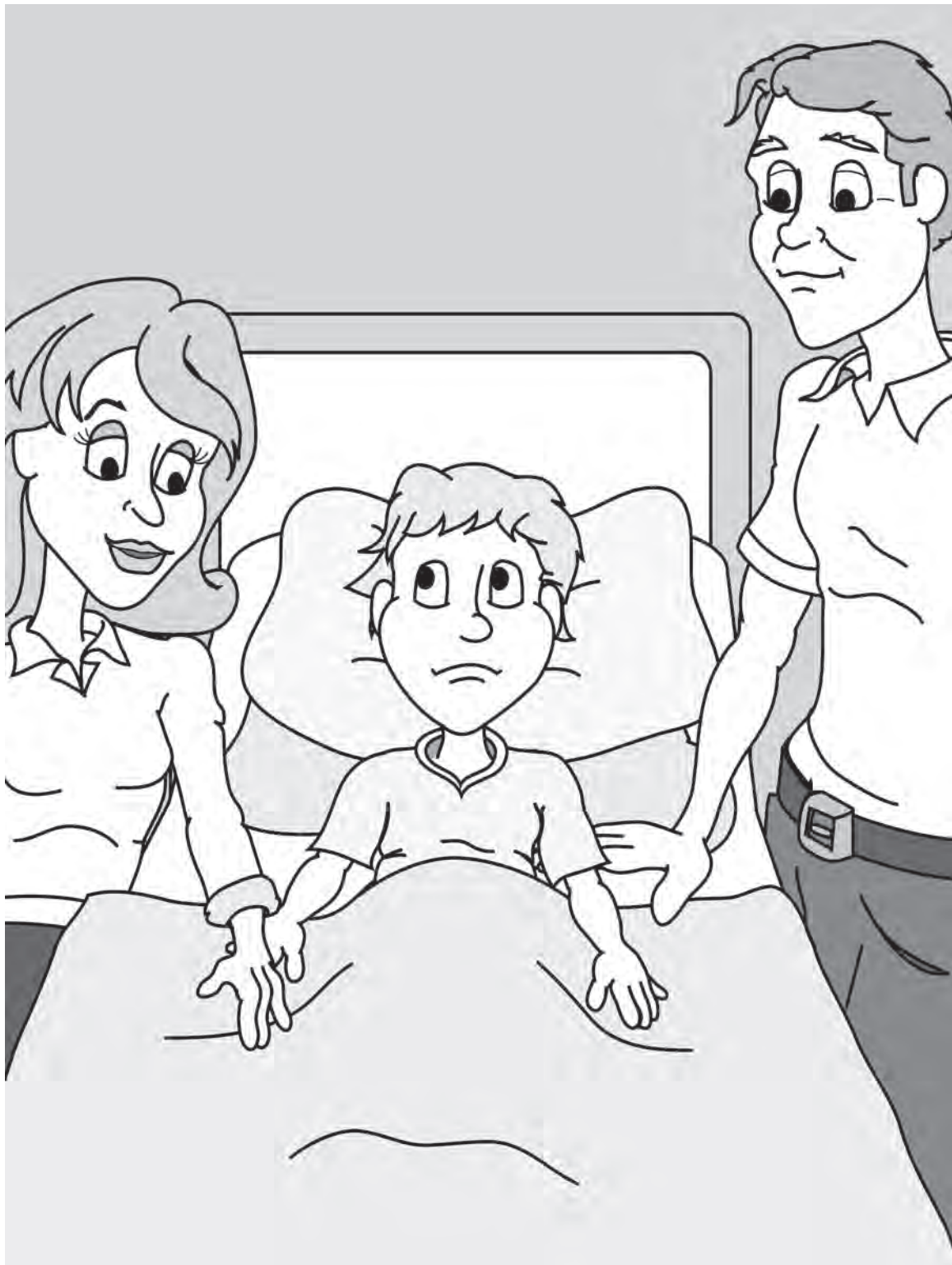
“Will it hurt when the food goes through the tube?” asked Jeremy.

“No,” said Dr. Paul.

“How do they put in the tube?” asked Jeremy.

“You will have an operation at the hospital. They will give you special medicine that makes you fall asleep and stay asleep while I put in the g-tube,” said Dr. Paul. “It might hurt a little when you first wake up, but we will give you medicine to stop it from hurting. Then, in a few days, it won’t hurt at all.”

Jeremy felt scared to go to the hospital, but he wanted to have the energy to ride his bike and catch tadpoles and play in his tree house.



Jeremy went to the hospital with his mom and dad. He felt nervous and scared and even a little excited. The mixed up feelings made his body seem jumpy and tingly inside.

“Jeremy Jones,” called a nurse.

Jeremy and his parents went into a gleaming white hospital room. He put on the hospital pajamas and lay down in the bed. The nurse took his temperature and his blood pressure. Then, while his mom and dad held his hand, the nurse cleaned his other hand with a wet alcohol wipe.

“What are you doing?” asked Jeremy.

“I’m just cleaning your hand. In a second, I will give you a small shot,” said the nurse. Jeremy’s eyes opened big with fear.

“It’s okay. You will feel a small pinch for a minute and then it will stop hurting,” said the nurse. “I need to put in an IV.”

“What’s an IV?”

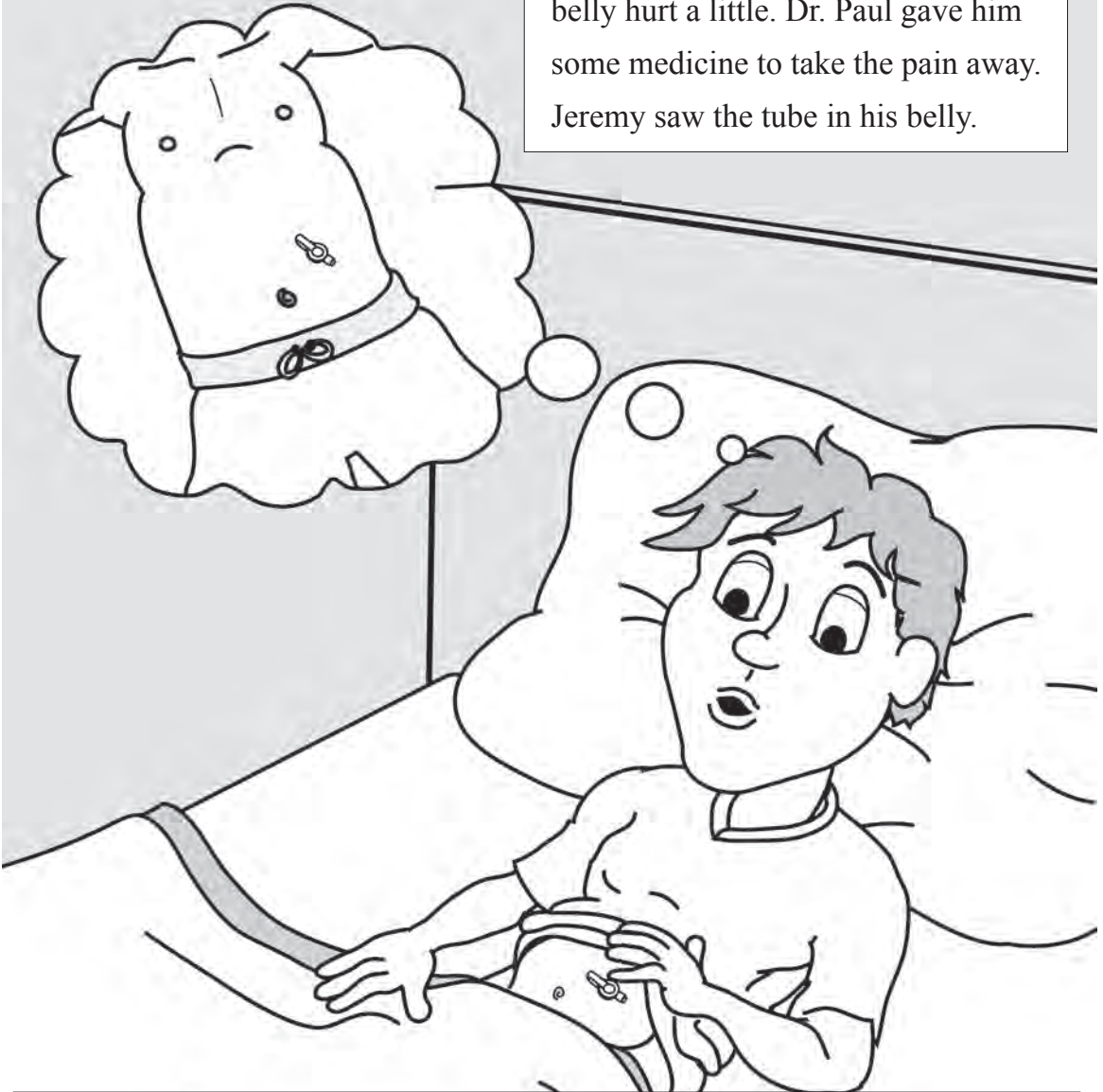
“It’s a tiny tube that goes into your vein.”

“Another tube!” Jeremy said with surprise.

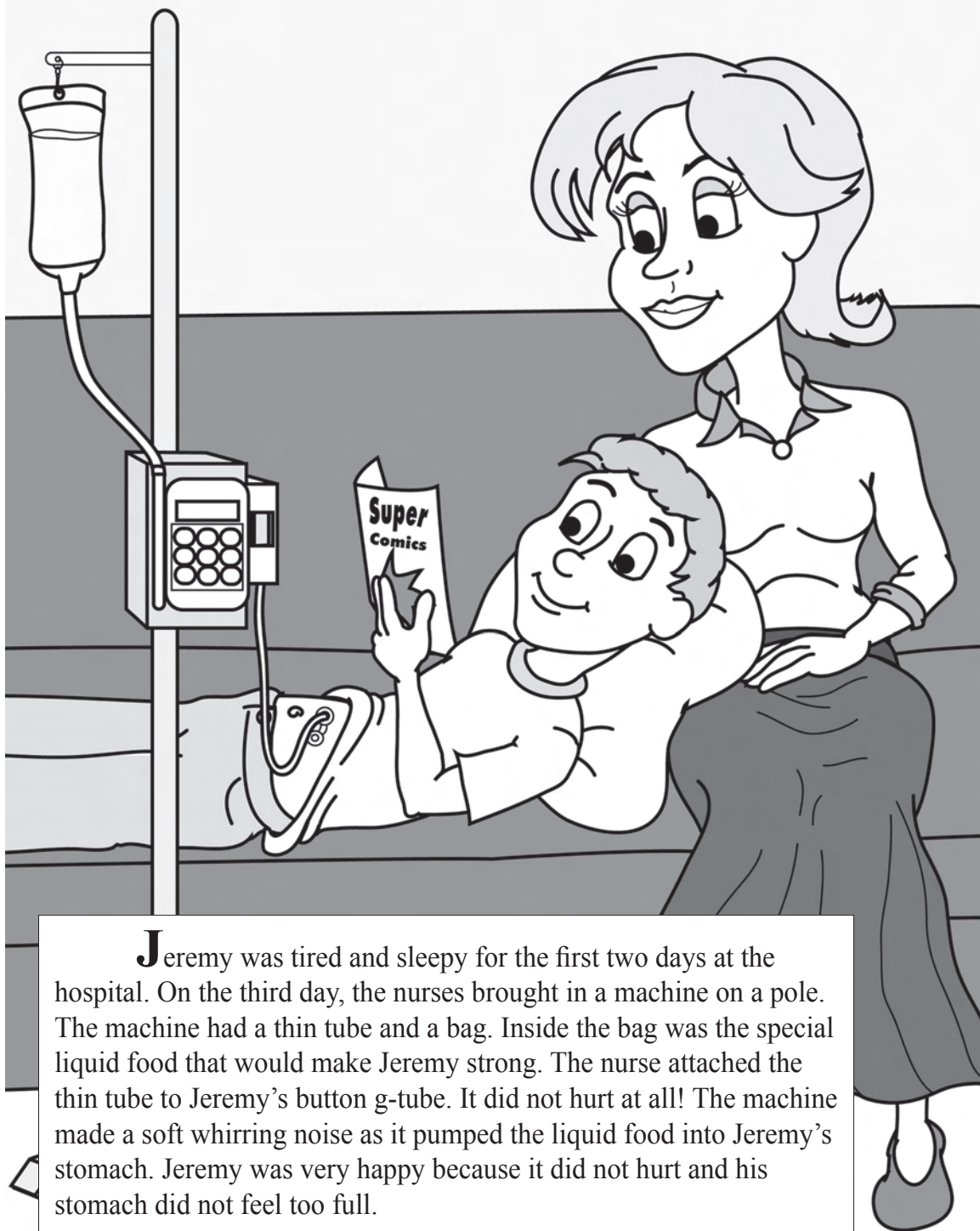
“Yes, but this tube only stays in while you are in the hospital. It gives you medicine so you can fall asleep and medicine to take the pain away when you wake up.”

Jeremy closed his eyes while the nurse put in the IV. It pinched a bit and then stopped hurting. The doctor put in the medicine and Jeremy quickly fell asleep.

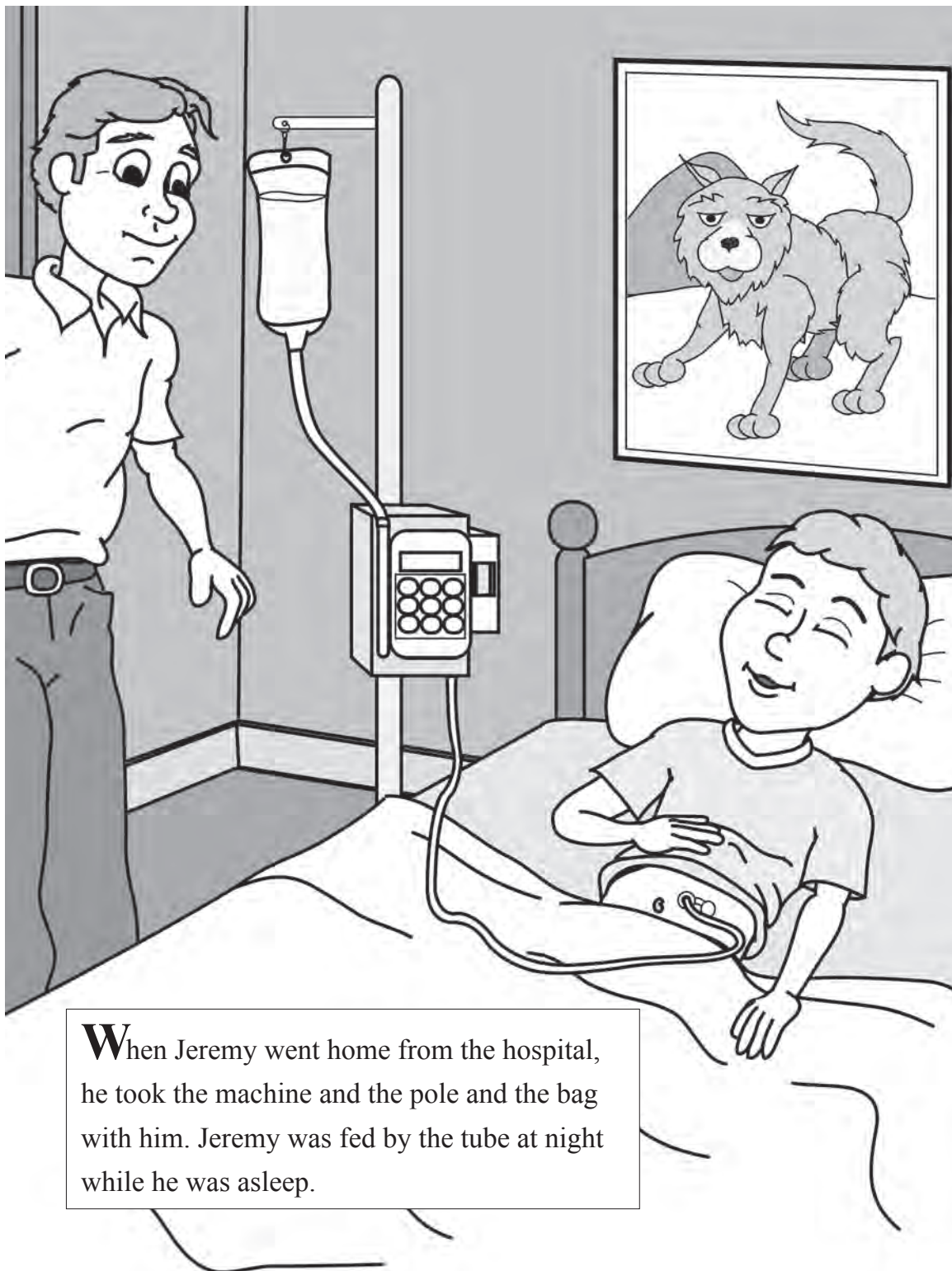
When Jeremy woke up, his belly hurt a little. Dr. Paul gave him some medicine to take the pain away. Jeremy saw the tube in his belly.



“Hey, it looks like a little button!” exclaimed Jeremy.
“Inside the button is the tiny g-tube, or straw, that goes into your stomach,” explained Dr. Paul.
“How does it stay in?” asked Jeremy.
“The tube has a tiny balloon inside your stomach and it keeps your tube from falling out,” said Dr. Paul. “Now, get some rest and you will feel better soon.”



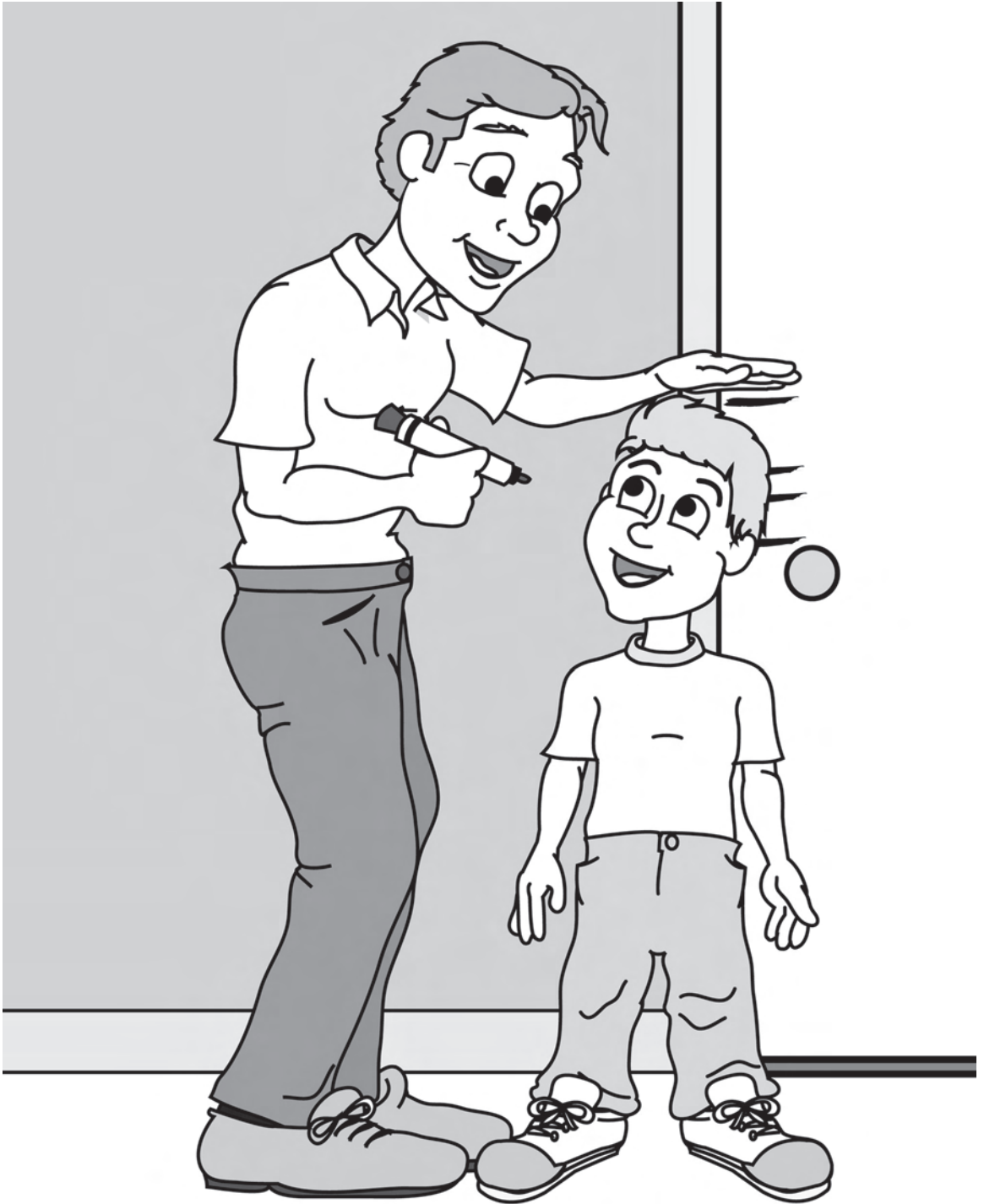
Jeremy was tired and sleepy for the first two days at the hospital. On the third day, the nurses brought in a machine on a pole. The machine had a thin tube and a bag. Inside the bag was the special liquid food that would make Jeremy strong. The nurse attached the thin tube to Jeremy's button g-tube. It did not hurt at all! The machine made a soft whirring noise as it pumped the liquid food into Jeremy's stomach. Jeremy was very happy because it did not hurt and his stomach did not feel too full.



When Jeremy went home from the hospital, he took the machine and the pole and the bag with him. Jeremy was fed by the tube at night while he was asleep.



During the day, no one could see Jeremy's g-tube unless he showed it to them, because it was hidden under his t-shirt. Soon Jeremy stopped feeling so tired and so sick.



The tube food helped Jeremy grow. He grew strong and tall.

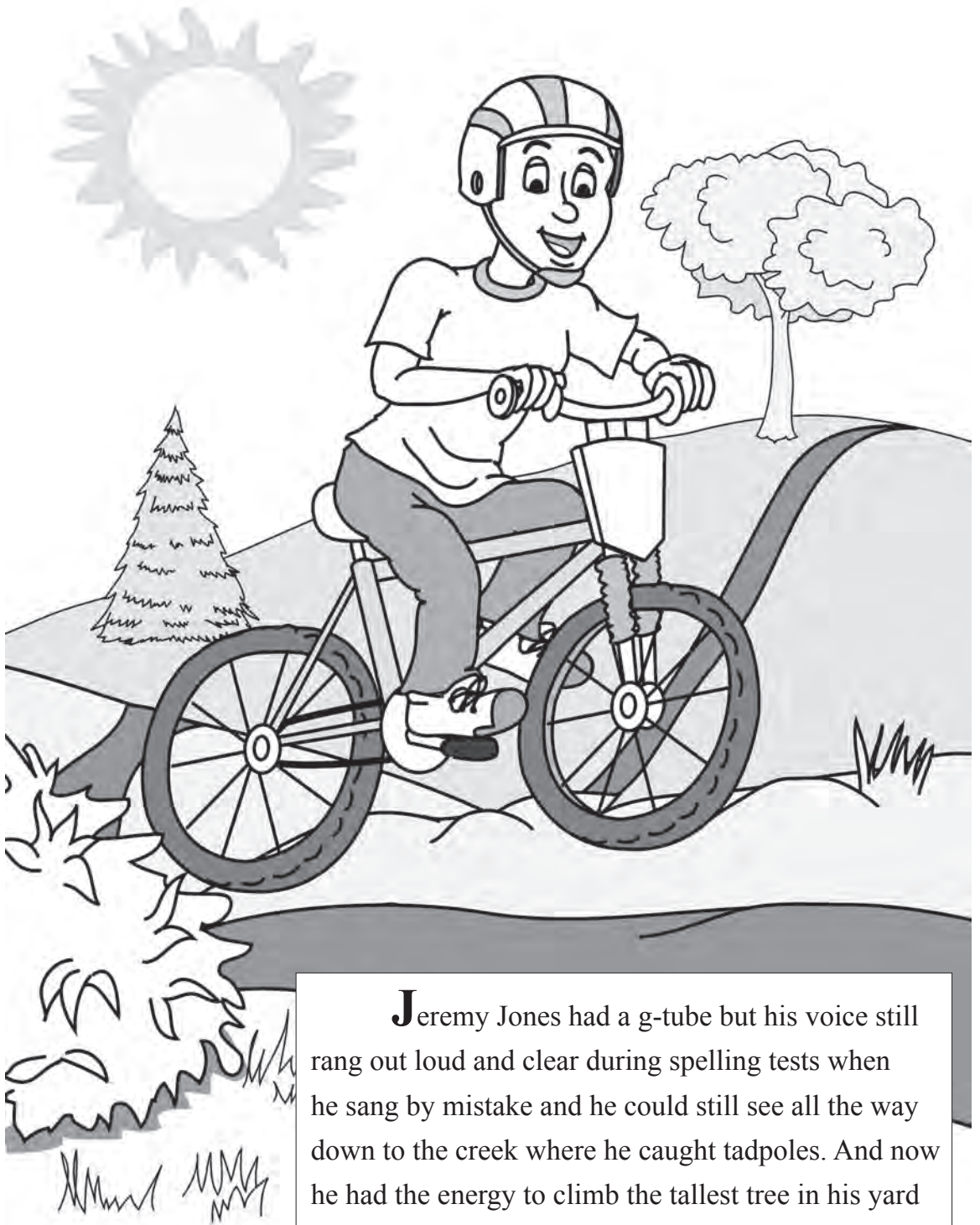
When people asked Jeremy why he had a tube, he said it was a magic tube that made him grow.



“Sometimes people wear glasses because their eyes don’t work well and sometimes people have wheelchairs because their legs don’t work well. I have a g-tube because my stomach doesn’t work well,” explained Jeremy.



As Jeremy grew taller, his body sometimes needed tube food during the day. Then, Jeremy wore a backpack that carried the bag of liquid food and the pump.



Jeremy Jones had a g-tube but his voice still rang out loud and clear during spelling tests when he sang by mistake and he could still see all the way down to the creek where he caught tadpoles. And now he had the energy to climb the tallest tree in his yard and ride his bike as fast as the wind. THE END.

QUESTIONS & ANSWERS

Question: When I have my feeding tube, can I still go swimming?

Answer: Yes! The doctor will tell you how long you have to wait after the operation before you can swim again.

Question: Do I have to wear something to cover my g-tube when I swim? **Answer:**

Some doctors recommend covering the g-tube with a waterproof bandage. Check with your doctor to find out where and when you have to cover your g-tube to swim. Sometimes boys wear t-shirts or surf shirts if they want to keep their g-tube private.

Question: Can I still play sports?

Answer: Non-contact sports will probably be best. Check with your doctor to find out what sports you can still play. You will have to be careful not to get hit hard in the stomach. This would hurt and might cause the skin around your g-tube to tear.

Question: What do I do at mealtimes at school?

Answer: Kids do different things. Depending on the reason for the g-tube, some kids are allowed to eat or drink a small amount. Some kids wear their pump during mealtimes in the cafeteria. Kids that can't eat or drink sometimes hang out with their friends and talk. Others get an extra long recess or special time to play on the computers at school.

Question: I know Jeremy needs his g-tube because his stomach is so slow digesting regular food, but I know there are other reasons kids need g-tubes. What are the other reasons kids need g-tubes?

Answer: Children need g-tubes for lots of different reasons. Sometimes, like Jeremy, they have something called gastric dysmotility. That is when the stomach and the intestines aren't able to push regular food through the stomach and intestines. Other times, the way a child's mouth or throat is shaped keeps them from eating through their mouth. Babies who are born too early are sometimes not strong enough to suck on a bottle and then they have g-tubes for a while.



QUESTIONS & ANSWERS

Question: Did I do something wrong that made me have to have a g-tube?

Answer: No! It is no one's fault that you had to have a g-tube. You didn't do anything wrong and neither did your parents. It is simply that a part of your body doesn't work well enough to let you eat by mouth. You actually did something right! You got help!

Question: Do all g-tubes look the same?

Answer: No. Some g-tubes are bigger and some are smaller. Often the first tube a child gets is fairly large when compared to the small button. The larger tube is usually a disc with a thin tube about 8 inches long coming out. The disc lies flat against the stomach and the tube can be taped against the stomach. The doctors often replace this tube with a small mic-key button or another type of smaller tube after the skin and stomach have healed. The changing of the tubes usually does not require an operation and children are usually not in the hospital overnight. After a period of time, tubes or buttons need changing. This can often be done by parents at home or during an office visit with a doctor.

Question: How long will I have to have a g-tube?

Answer: Some kids only have their g-tubes for a little while, others have them their whole life. It depends on the reason for the g-tube. This is an important question for you or your parents to ask your doctor.



About the Author...

Anne Reckling, PsyD is a licensed psychologist specializing in the treatment of children and adolescents. She and her husband have two children; Sam (age 10) and Asher (age 5). Asher has Mitochondrial Disease which has resulted in intestinal dysmotility. Because of the damage to his stomach and intestines, he has a g-tube and a cecostomy tube. They live in Columbus, Ohio.



About the Illustrator...



Timothy O'Halloran is a Graphic Artist and Cartoonist whose work includes graphic design, children's books, illustration and painting. Tim's niece and nephews have Mitochondrial Disease. He lives in Dania Beach, Florida.