

The Feeding Tube

A feeding tube as a helpful extra way to give their body food, water and sometimes medicine when eating or drinking is difficult



What is a feeding tube?

Your feeding tube is a little helper for your tummy.

Sometimes Pompe disease can make the muscles used for eating and swallowing weaker. This can make eating take a long time or make it difficult to get enough food and drinks.



A feeding tube gives your body another way to get the energy, food and water it needs to grow, play and keep going.

It doesn't mean you can't be a normal kid.

You can still smile, talk, play and spend time with your family and friends.



Depending on what your healthcare team says, you may also still be able to eat and drink by mouth.



1. 😴 Sleepy time

Medicine helps you go to sleep, so you don't feel the procedure.

2. 🔍 The doctors look at your tummy. A tiny camera helps the doctors see the stomach and choose the right place.

3. 🔪 A small opening is made A small opening is made through the tummy wall.

4. 🍼 The feeding tube is placed. The tube goes through the opening and into the stomach.

5. ❤️ The tube is held safely in place. Special parts inside and outside the tummy stop it from slipping out.

6. 🌈 Wake up. When you wake up, the tube is there to help give your body the food and fluids it needs.

The exact method varies according to the type of gastrostomy being used, so the child's hospital team will explain the particular procedure beforehand.



"Eating can sometimes be hard"

Pompe disease can make the muscles used for eating and swallowing weaker.

This can make eating take a **long time** or make it **difficult** to get **enough** food and **drinks**.

You are not alone. We are here to help.

Small steps, **extra support** and lots of love can make a big difference.



Meet my feeding tube

My feeding tube helps my body get the **food, fluids and nutrients** it needs to grow, play and stay strong!

How it works

- 1 The tube goes through a small **opening** in my tummy.
- 2 It travels through my tummy wall into my stomach.
- 3 The balloon inside my stomach keeps it safe and in the **right place**.

On the outside (bumper)
The tube →
Inside my tummy (balloon)
Tummy wall
Stomach

It's a helper that gives me the **energy** I need every day!

I can still smile, play, talk and spend time with my family and friends!

My healthcare team is here to help me and answer any questions.



How it helps

My feeding tube gives my body the nutrition and fluids it needs to grow, play and enjoy every day!

It helps me:

- ENERGY**
Gives me energy so I can play, learn and have fun!
- GROWTH**
Helps me grow strong and healthy inside and out!
- HYDRATION**
Keeps me hydrated and helps my body work its best!

It's a small tube with a **BIG** job!

My feeding tube is a helper that supports me every day so I can be **ME!**

I can play
I can learn
I can enjoy time with my friends

Different doesn't mean less. It means I have what I need to **shine!**



Meet my feeding tube

How it helps

Liquid nutrition (food, water and vitamins) travels through the tube into my stomach.

Energy
Growth
Hydration

I'm still me!

The feeding tube doesn't stop me from doing the things I love!

I can play, laugh, learn and be a great friend!

How it works

- 1 The tube goes through a small opening in my tummy.
- 2 It travels through my tummy wall into my stomach.
- 3 The balloon inside my stomach keeps it safe and in the **right place**.

I'm still me!

I'm the same kid with the same dreams, the same smile and the same love for fun!

My feeding tube helps me stay strong so I can enjoy every awesome day!

Thank you for understanding and being part of my **journey!**