



Let's Learn



About PIPO  
(Paediatric Intestinal Pseudo Obstruction)

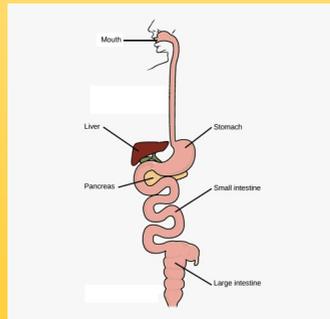
# FAST FACTS

Pseudo Obstruction is an illness of the digestive system. It affects how it moves.

The digestive tract is a hollow tube from the mouth to the end of the large intestine (anus).



The digestive tract



You can be born with the disease. Other times you may develop it later on. Sometimes it is mild, other times it can be severe. It is not something you can catch from other people. It affects the nerves and/or muscles in the digestive tract.

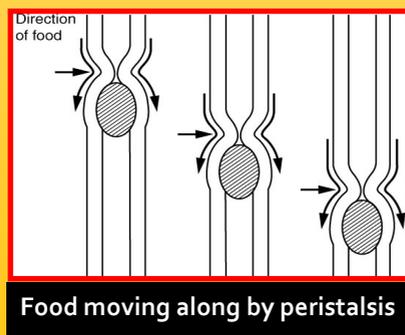


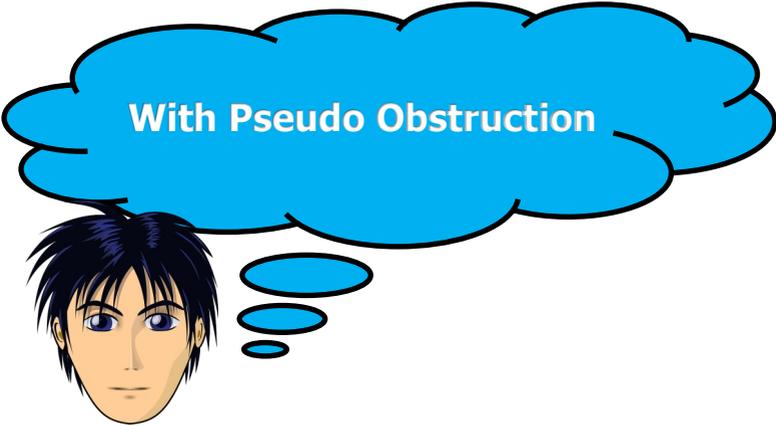
Normally when we eat food, chewing starts to break it down into smaller bits in the mouth. This is then moved into the stomach and then the intestines/bowel.

The small intestine carries out almost all of the absorption of nutrition of food into the blood. The large intestine /bowel absorbs water and salts from the food that has not been digested, and gets rid of waste left over. We then get a feeling of needing to go the toilet, to go for a poo.



Muscles, nerves and chemical messages cause the digestive tract to squeeze the contents along. This movement is called peristalsis.





## With Pseudo Obstruction

**The digestive tract does not move as it should. It always affects the small bowel, but sometimes can also involve other parts of the gut, like stomach and large intestine. Sometimes it can be in all parts.**

**The muscles and nerves do not work as they should so they do not squeeze the contents along. For some people, the digestive tract does not move as it should, for others it may barely move at all.**

**Some children also have 'crisis' or 'flares' where there may be times when the digestive tract barely moves or stops, and this may mean they end up in hospital, but then at other times it works better.**





Everyone is different but lots of children with PIPO find that they get tummy pain and sickness. Other common problems are bloating, constipation, diarrhoea, reflux, and difficulties with tolerating a normal diet.

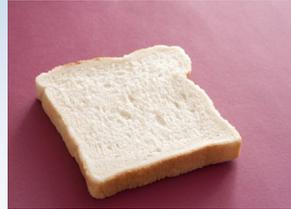
The bowel behaves like there is something causing a blockage but there is not actually anything there. Instead, it is because the muscles and nerves, in the digestive tract, are not working properly.

A good way to picture what ends up happening in the digestive tract, in someone with PIPO, is thinking of it like a blocked drain.



## FOOD AND DRINK

**Your team may advise you to change what you eat and drink to help improve some symptoms. Some people find that eating foods that are lower in fat and fibre are easier to tolerate.**



**Also looking at when and how often you eat can help; eating little and often rather than large meals may be better.**



**Your team may suggest that only bite and dissolve texture foods can be eaten. These are foods such as puff crisps, as they melt away easily in the mouth before you swallow them. As it is difficult to get all the nutrition you need from these types of food, you may be advised to drink special medical milkshakes that contain lots of nutrition to get everything you need.**



There are also medicines that can help the gastrointestinal tract move better. Other medicines can be given to help with pain and sickness. Some stronger painkillers can make the bowel worse, so your doctor may not be so keen for you to have these. There are some medicines that can be used for pain that were made for other illnesses. Sometimes these can be helpful.



**There are other things that you may find useful when in pain.**

**You could try:**

- ◆ **A hot water bottle**
- **Moving about/doing some exercise**
- **Listening to some music**
- **Watching some tv**
- **Sipping on a warm drink**
- **Taking some deep breaths**
- **Having a warm bath**
- **Having a rest/sleep**





A surgeon may do an operation and make a stoma.

A stoma is an opening on the outside of the tummy. A bag is then worn over the hole, which collects the poo. This can help a lot with pain and sickness. It can have the effect of reducing the problems of a blocked drain, and can help some people eat.

Having a stoma takes a little time to get used to, but it doesn't need to stop you doing anything, including swimming or having a bath.



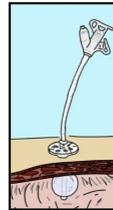
## Liquid Nutrition and tubes



For some children it is easier for their digestive systems to have liquids. There are milkshake based drinks and juice ones that have more nutrition in than most drinks. Your dietician may give you some of these to try.



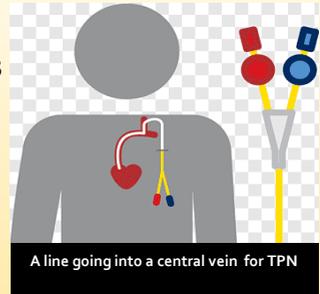
Sometimes you may need to go into hospital to have a tube. This might sound scary but it doesn't hurt. It means you can have a special liquid feed straight into either your stomach or small intestine/bowel.



The tube feeds will give you all the nutrition and goodness people get when they eat, to help you grow and be healthy. You may have bolus feeds a number of times a day, or you may have a pump which you can put into a backpack.

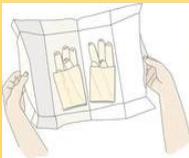
Sometimes tubes can be used for drainage/venting of the stomach. Some people find this helps them with their sickness and pain. Some people do this regularly and some when they have a 'flare'.

There is one more type of feeding that children with PIPO sometimes need. This is called TPN. It stands for Total Parental Nutrition. This basically means nutrition into the veins.



Sometimes, the digestive tract is not able to cope with nutrition or can only have very small amounts. TPN is a way to feed which doesn't need to use the digestive system. Isn't this clever?

To have this type of feeding at home your parents will have to do some training. When you get older you may be able to help or take over with this yourself. Some people have nurses come into their homes to do this for them. The reason the training is needed is because it is very important to do everything in a very clean (sterile) way, to try and avoid infections as the feed goes into a line that goes straight into a big vein.



While you are on this type of feeding your doctors will keep a close eye on you, and you will be checked regularly to make sure everything is going well for you.



The doctors will decide what treatments are best for you. You may have to go into hospital to have some tests. Try not to worry about this. You will be allowed someone with you, and you can ask as many questions as you like. You may be given a timetable to explain what will happen each day. The tests will give the doctors a better idea of what is happening, with your digestive tract, and what might help you best.



Some of these tests will be very simple, like an x-ray. X-rays are quick and do not hurt at all. They take pictures of the inside of the body.

To get more information the doctors might want you to have other tests to look at how your digestive system is working. You may have to drink or eat something, and then you may have some pictures taken so the doctors can look at how this moves through your digestive tract, including your stomach and intestines.

You may have to go in a big scanner. One of these is called an MRI



(Magnetic Resonance Imaging). It uses magnets, radio waves and a computer to make detailed pictures. This is a bit like going in a big spacecraft. It may be a bit noisy but don't worry you will be given some earplugs.

Some hospitals do tests called manometries. These are clever tests as they can look at the strength and coordination of contractions in the bowel (if the bowel movements are strong or weak, and whether it moves as it should). They do this by sensors on a tube - it's a bit like science fiction! The tube (catheter) is placed either through your nose (or stomach if you have a feeding tube) to test the small bowel or through your bottom (or mucous fistula if you have a stoma) to test the large bowel. This usually happens whilst you are asleep (under anaesthetic).



This information booklet has been produced by the Pseudo Obstruction Research Trust, with the help of the Gastroenterology team at GOSH, for children.

Pseudo Obstruction Research Trust

*The Pseudo Obstruction Research Trust was formed in 2006, by Sue Stewart and Sonia Frost, in Sonia's daughter Emily's legacy.*

*The aim of the charity is to fund research into CIPO (Chronic Intestinal Pseudo Obstruction), whilst also raising awareness into the illness, and improving understanding and treatment options.*

*The charity also provides support to patients and their families. We have a thriving Facebook support group, and are always open to people messaging, and emailing for support. Also, we are always grateful for anyone who wishes to fundraise for us.*

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