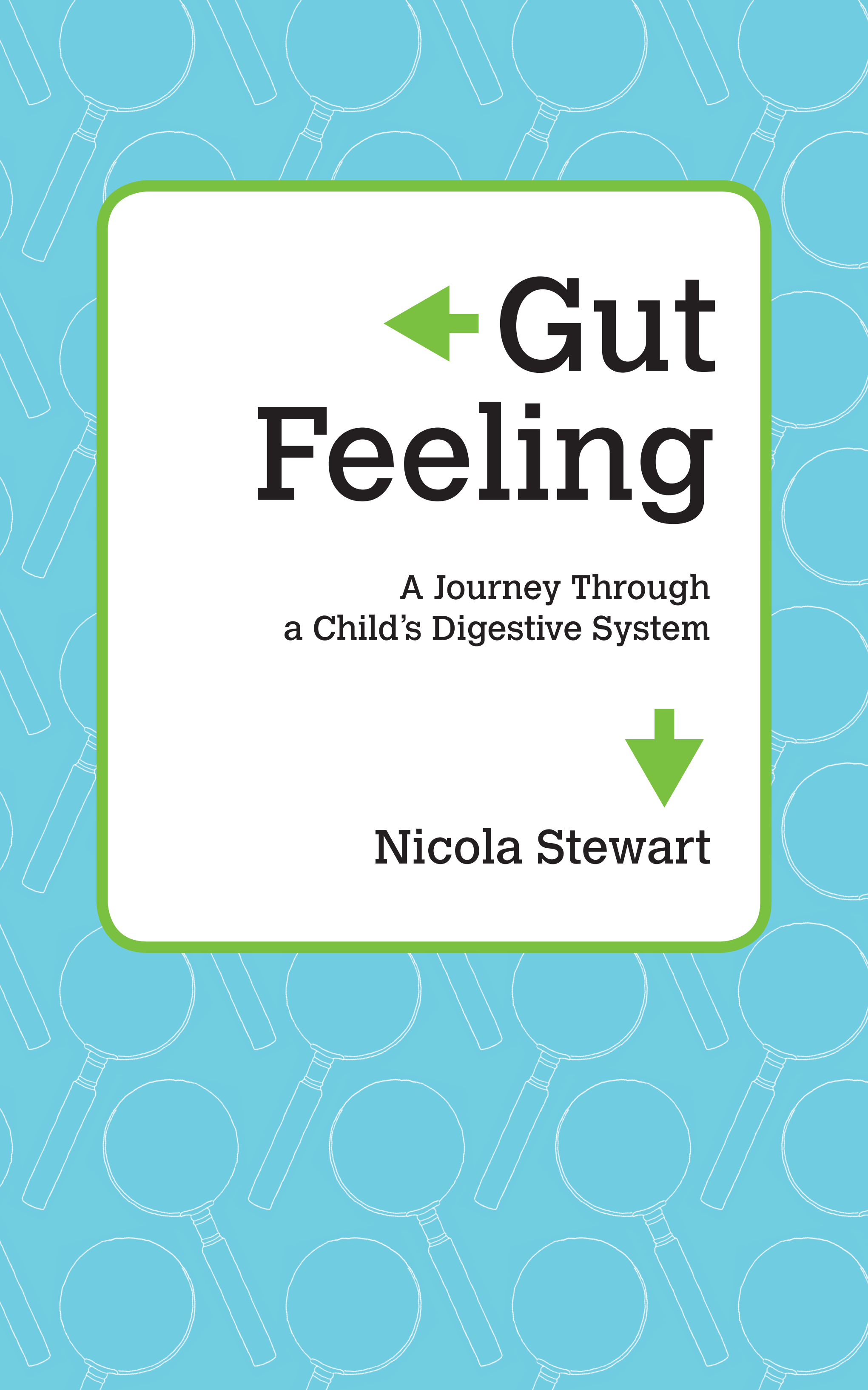


Gut Feeling

A Journey Through a Child's Digestive System

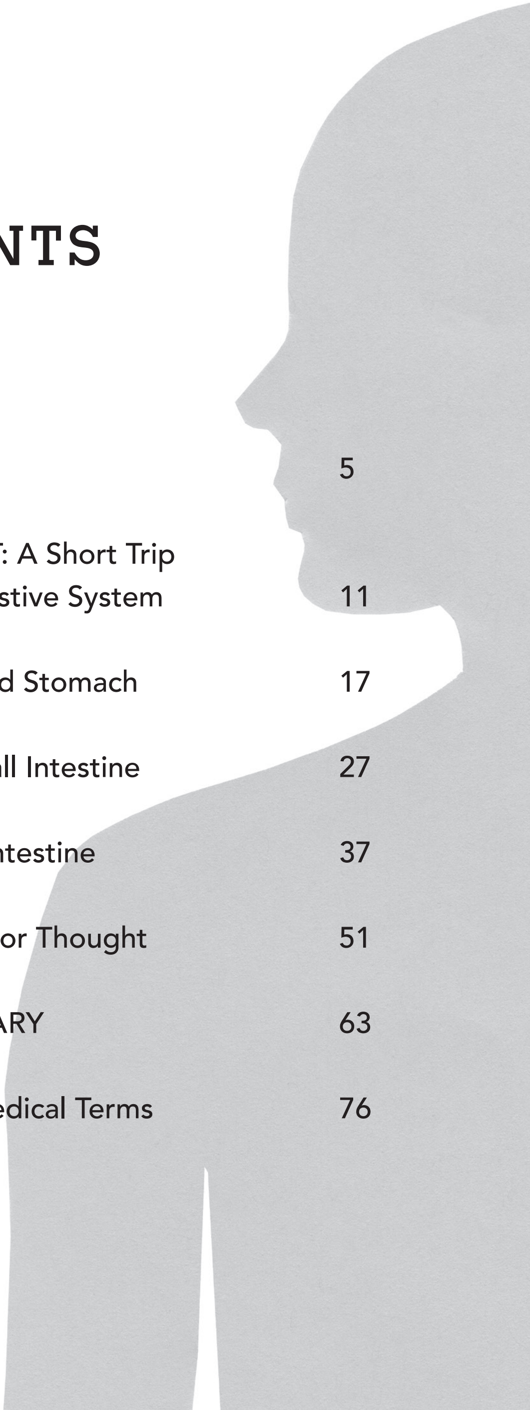
Nicola Stewart

“THERE IS NO SHORTAGE of books about the gastrointestinal tract, however, when Nicola promised to write something exceptional she truly delivered. *Gut Feeling* takes you on a journey through the gastrointestinal system and navigates the complexity of medical jargon by guiding the reader through Nicola and her family’s struggle to understand Spike’s illness.

From ‘Our Story’ to ‘In’, ‘Along’ and ‘Out’ the book will follow food from ingestion to excretion. Each chapter will explain how different parts of the digestive process work then talks about what ‘could go wrong’. There are fascinating ‘fun facts to share with your child’ and simplified descriptions of common disorders, investigations and treatments. All sections are supplemented with diagrams and illustrations.

Gut Feeling will provide a bridge between children and their families on one side and the health care profession with their complex maze of medical terminology and jargon on the other side.“

Dr Mohamed Mutalib – consultant for children’s gastroenterology, Evelina London Children’s Hospital



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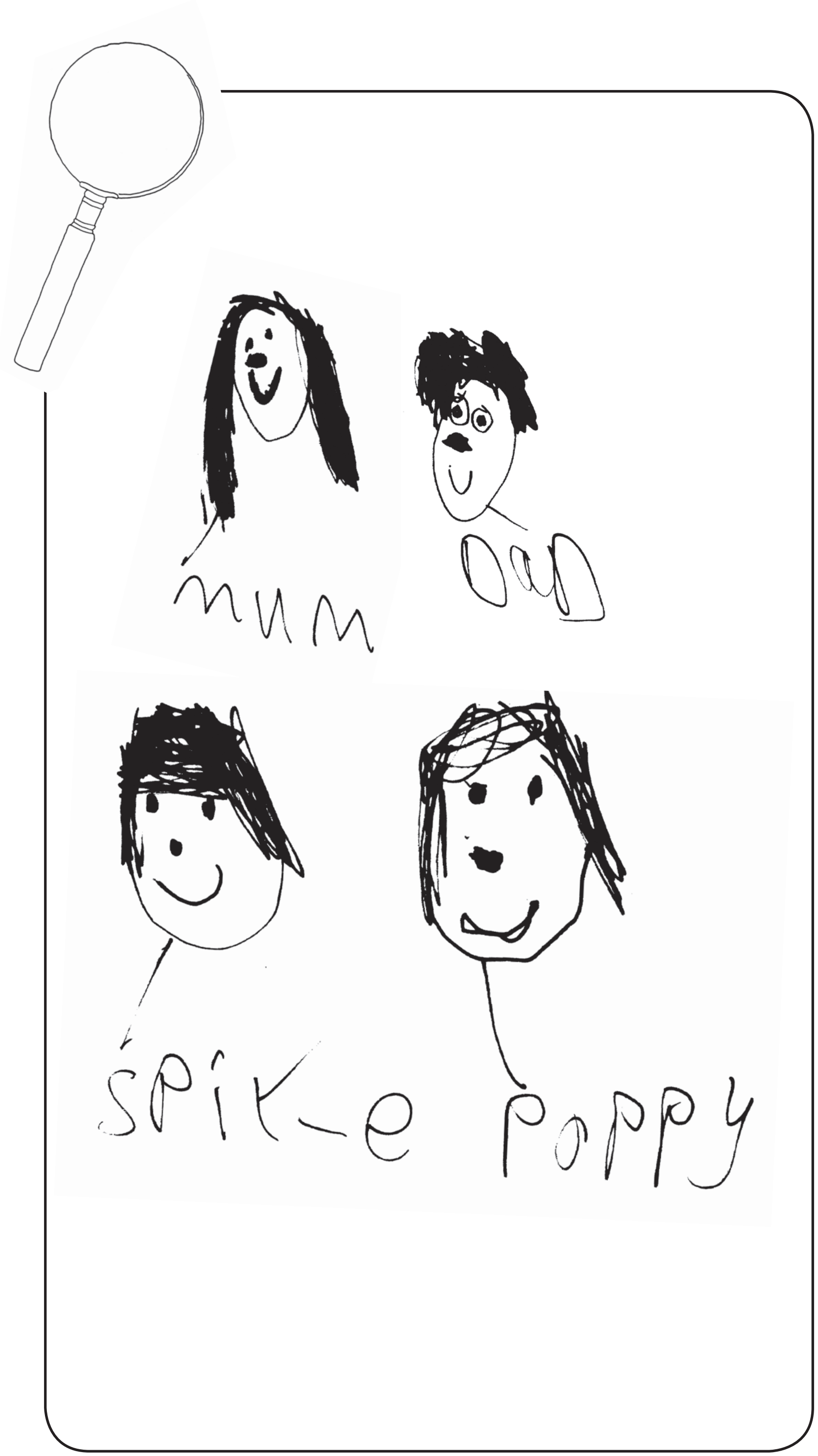


OUR STORY

Spike, currently an eccentric and energetic 9 year old, was born 4 months prematurely at what is called 'the limit of viability' and was given a 6% chance of survival. He spent the first months of his life in a high-tech intensive care capsule and was afflicted with several serious problems associated with being born so early. He nearly died on more than one occasion but finally came home when he was 3 months old. We were daunted by his condition but generally believed things would be fine from then on.

We were wrong.

Immediately Spike proved to be a vigorous, frequent vomiter. As a result, he suffered chest infection after chest infection and spent more time back in hospital than out. We tried all sorts of things including dairy-

free, soya-free and gluten-free diets but nothing stayed down. He had various tubes inserted so we could feed him through his nose into his tummy or his small intestine and even through a gastrostomy (a tube inserted through a hole in his stomach) but these still didn't prevent food and fluids passing into his lungs.

So at the age of 3 he had a fundoplication, an operation that tightened the top of his stomach to prevent him from vomiting. Unfortunately, under the pressure of surgery, his lungs collapsed and he spent 9 hours in the operating theatre while the medical team tried to resuscitate him and complete the operation. His chances of survival were already looking low when, within a week and still on life support, he was rushed back into theatre with a condition called necrotizing enterocolitis (NEC); tissue in parts of his bowel had died and holes had developed causing an acute infection. We spent another turbulent six weeks in intensive care.

As you can imagine, it was a very anxious time.

But, when Spike finally came home again, he was a changed child. He stopped vomiting and started to enjoy a limited diet of dry, beige foods – basically crackers and bread sticks. We were so relieved that he was eating at all that he was allowed to choose whatever foods he wanted to on top of his regular tube feeds. We enjoyed a happy few weeks but it quickly became apparent that there was a major problem; he was painfully constipated. His abdomen was distended, and became enormous. He was in increasing pain and struggling to breathe. So it was back to experiments in eliminating various food types, giving him laxatives (quite ineffective), suppositories (totally ineffective), rectal washouts (exhausting and rather nasty for everybody concerned) plus a variety of tests including x-rays, barium studies, biopsies, an endoscopy, a colonoscopy and a manometry. They showed that Spike's large intestine had stopped working. Life was miserable, messy and very anxious.

Finally, he was diagnosed with something called chronic intestinal pseudo obstruction (CIPO), a condition where the muscles and nerves that work together to propel food and poo along the intestine don't work. The only option available seemed to be for him to have yet another procedure called an ileostomy. This is an operation that creates an opening in the abdomen to drain poo straight from the small intestine into an external bag which is emptied by hand. We had agonized over agreeing to go ahead as it seemed such a drastic and life-changing intervention but, despite our worries, it turned out to be a very positive step. And even with the rapid learning curve involved in *dealing with the daily emptying and changing of his bag, it restored a relative sense of normality to our life.*

Today Spike is happy and thriving. He rarely aspirates; he has his ileostomy bag to collect poo that would normally come out of his bottom and his gastrostomy so we can give him medicine, vitamins and fluid directly into his stomach. At long last, it is safe for him to eat, and he eats what works for him – still generally dry beige food. He never willingly eats a vegetable!

Each stage of the journey to this point was confusing, upsetting and often exhausting. Many of the things that Spike continues to experience are painful, invasive and very unpleasant for him and the whole family.

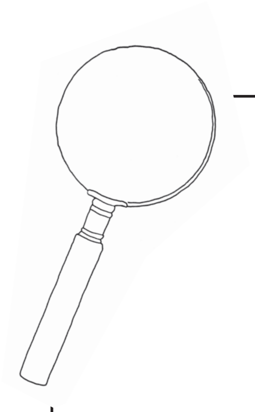
One of the main problems we experienced was that we often didn't understand what was going on or have the time or energy to do our own research. Consultants would draw pictures on scraps of paper, nurses would try to explain what they were doing, and staff in the operating theatres were reassuring. But the bottom line is that these are medical experts; they are not artists or teachers and when you and your child are in a stressful situation it's really difficult to understand and absorb exactly what is happening. There is a lot of information to take in and difficult, sometimes life-changing decisions to be made.

Often we would think we understood, or say that we did because we felt we were supposed to. We would agree to plans of action only to later forget: was it once or twice a day? Did they say 'A' or did they say 'B'? We often wished we had something to help us understand, a way to help alleviate the anxiety and explain what was going on to Spike, to Poppy his sister and to the rest of our family and friends.

The more I learn about the gut the more amazed I become. We take it for granted and yet it is extraordinarily sophisticated and communicative. Teaching Spike to be conscious of its signs and sensations has I believe given him more control over managing his condition and it has certainly given me more confidence to care for him.

I hope this simple guide helps you and your family 'digest' and understand the Digestive System.

We have designed this book for you to make it your own – draw in it, colour it, write notes in it. Use it to ask questions and to get answers. Colouring the illustrations can help you get to know the gut better.



Notes and Questions

→ IN
ALONG ↲
↓ OUT

From kitchen to bathroom,
from gums to bums

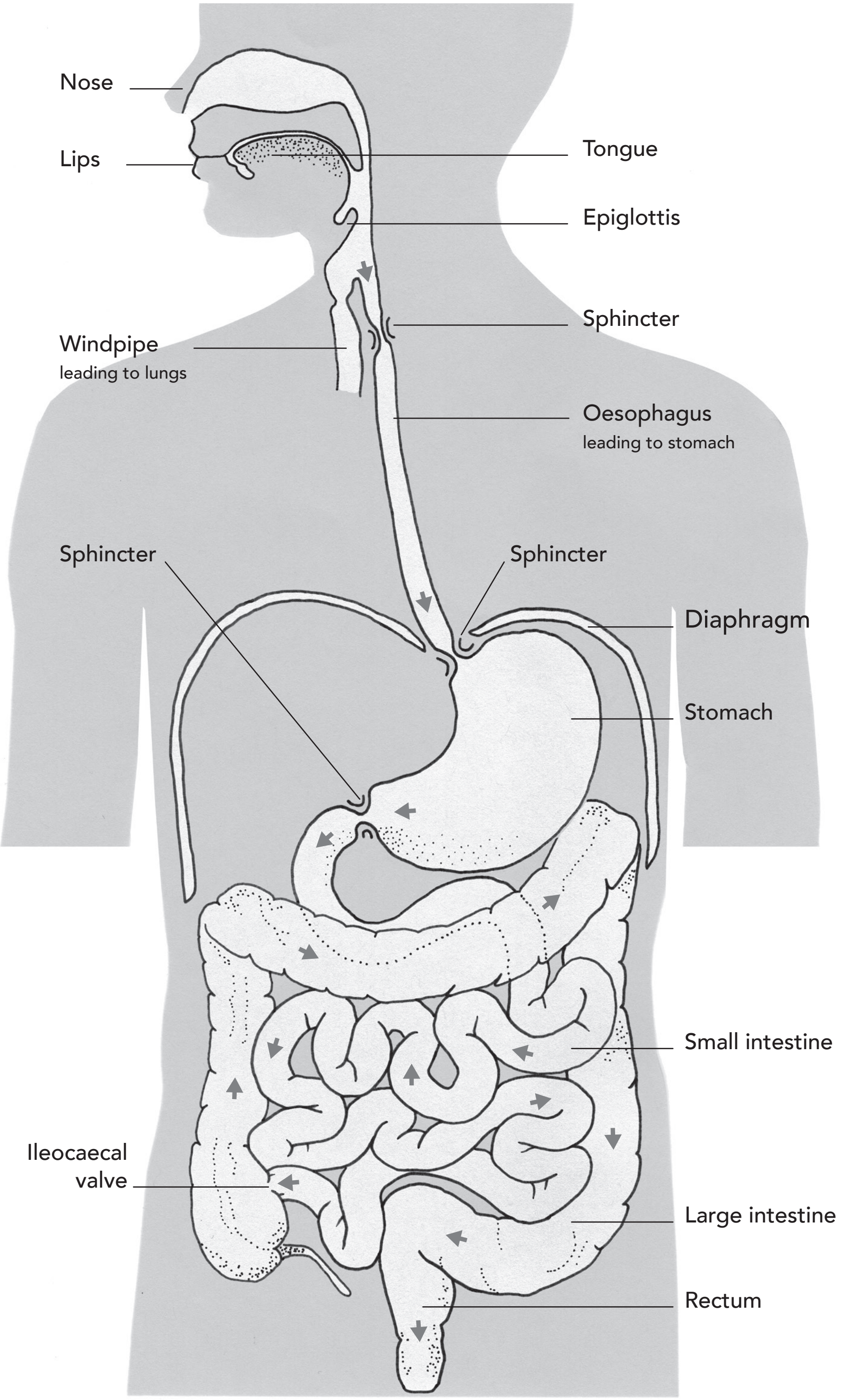
The parts of our body that make up the digestive system are together called the Gastro Intestinal Tract, the GI Tract or simply the Gut. Their function is to break food into minute pieces, extract and absorb the nutrients and get rid of any waste.

The GI tract is a long tube of muscles and nerves (the enteric nervous system) that work together to create movement from the moment food enters our mouth until the waste remnants come out the other end as poo (which medical people often call stool or faeces). This is called mechanical digestion.

The liver, gallbladder and pancreas produce and release chemicals called digestive enzymes that react with the food we have eaten. This is called chemical digestion.

The three sections of the gut: from the mouth to the stomach; from the stomach to the small intestine and from the small intestine to the large intestine, each have a different role. Each has a sphincter which is a valve or a 'door' of muscle which opens briefly to allow food to exit when it is ready to move onto the next section.

As food moves between the three sections, its consistency changes. By the time it reaches the small



intestine, it is liquid and nutrients are ready for absorption into the blood stream. Once in the blood, they are transported to the liver for distribution through the body, providing the energy we need to survive and thrive. Whatever remains passes into the large intestine where water is absorbed and poo is formed.

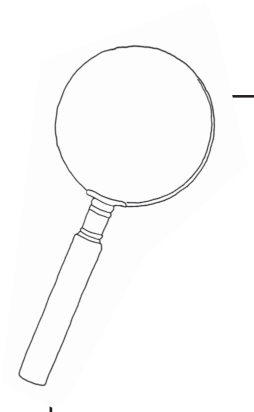
A healthy gut is never at rest. Every few seconds short sections will contract and relax in the movement called peristalisis which pushes food along and churns it as it goes.

The gut is extraordinarily robust and adaptable but many things can go wrong and cause problems. Some of these are minor and will be fixed naturally in time; others by a change in diet but some require medicines and even surgery.

Internal pain, exhaustion, changes in diet and unpredictable bowel habits can affect quality of life and need to be recognised. It is important that everyone involved in the care of your child understands their condition to be able to support them effectively and empathetically.

If you think your child is not getting the help they need or that something is wrong, never be afraid to ask.

YOU KNOW YOUR CHILD BEST



Notes and Questions

IN

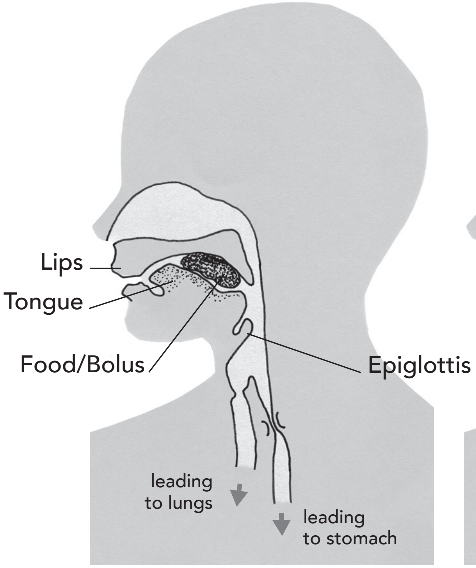
THE MOUTH AND STOMACH

The first section of the digestive tract is made up of our mouth, teeth, tongue, salivary glands, our throat, oesophagus and stomach.

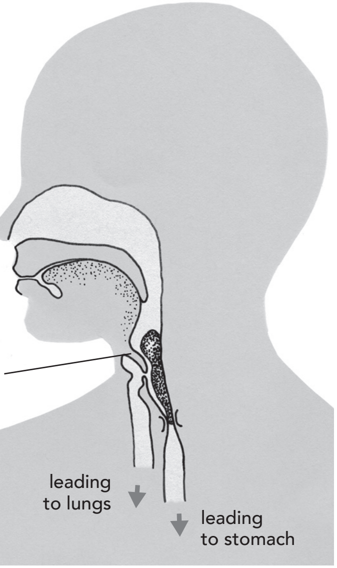
SO HOW DOES IT WORK?

It all starts with spit. Spit is the business!

We produce two types of spit or saliva. Unstimulated spit is the thick and sticky kind that is continually present in our mouth. It protects our gums and teeth from acid and traps bacteria which are later destroyed in the acidic environment of the stomach. Stimulated saliva is what we release when we smell, see or even think about food. It is 90% water and 10% digestive enzymes, mainly an enzyme called amylase which breaks down starchy food like bread, rice and pasta.



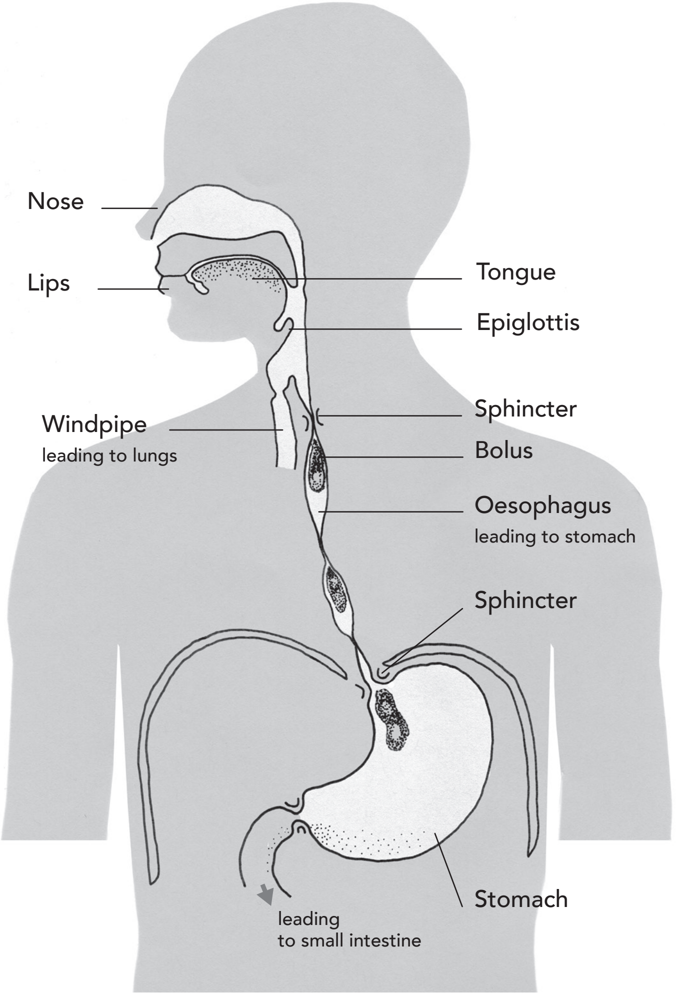
1 The Oral Phase



2 The Pharynegeal Phase

The tongue pushes food around our mouth, mixing it with saliva and positioning it for teeth to grind. When food is sufficiently soft, the tongue shapes it into a soft ball called a bolus and moves it to the back of the mouth where we swallow. This is the oral phase of digestion and we can consciously control it. From now on food is entirely under the control of our gut.

Next is the pharyngeal phase. Because our throat (the pharynx) contains both our windpipe (the trachea) and food pipe (the oesophagus), a series of movements automatically close our respiratory passages when we swallow. This allows food to pass into our oesophagus without us choking. We probably all know what this feels like if it fails; it makes us cough and splutter.



3 The Oesophageal Phase

Then, the muscles of the oesophagus relax and contract, squeezing the bolus towards the entrance of the stomach. Usually, this movement is in one direction only – down – but the gut muscles are so strong that theoretically we could eat whilst doing a headstand!

At the junction to the stomach, there is a ring of muscles called the lower oesophageal sphincter (LOS) which relaxes to allow the food to drop into the stomach and then closes to prevent it coming back up.

This next stage of the journey is where the serious process of digestion of food really gets going. Our stomach is not located where most of us believe it is. It starts just below our left nipple and ends below our right ribcage, much higher than we usually think. When the stomach is empty, it folds up but it can more than double in size to hold food and has amazing stretch receptors to tell us when we are full.

The stomach produces digestive acids to kill off harmful bacteria and start to breakdown proteins while the muscles squeeze and churn food into a lumpy liquid called chyme. Chyme is what we see when we vomit; it is the acid in it that makes our mouth burn and taste so vile.

The stomach is protected by a thick coating of mucus. This mucus is always adjusting its pH value and replaces itself every 3 days. A pH value is a measure of how strongly acid or alkaline something is (values from 0–6 are acidic, 7 is neutral, and 8–14 are alkaline). The stomach should have a pH value of roughly 2. Blood and water should have a neutral pH value of 7.

It takes between 2 to 6 hours for food to leave the stomach depending on what we have eaten. A meal higher in fats like steak and chips will take roughly 6 hours, whereas most fruit and vegetables move on in under 2 hours.

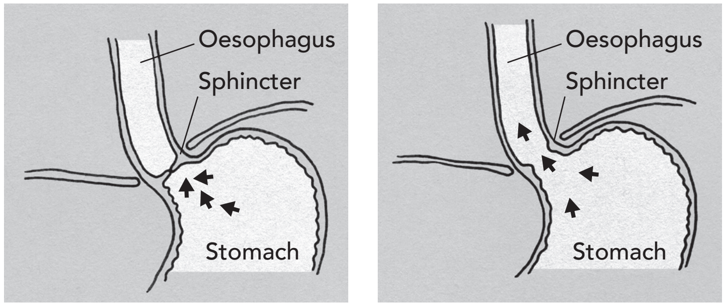
The first stage of our journey is over and when the chyme is in just the right state, the ring of muscles at the bottom of the stomach called the pylorus relaxes to allow it to pass through on the next stage of its journey into the small intestine.

BUT WHAT CAN GO WRONG?

UNSAFE SWALLOW is a term you may hear if your child is struggling to swallow food. It means that the mouth or throat muscles and the associated nerves lack co-ordination. Some children may need an operation to change the anatomy of their airway; most will grow beyond problems naturally when their anatomy matures as Spike did.

REFLUX (GORD) is a very common complaint. It occurs when contents of the stomach are forced back up through the lower oesophageal sphincter and into the oesophagus, throat or mouth.

Because the oesophagus runs directly behind the heart, we often think of the pain this causes as heartburn. Other symptoms include burping,



Picture showing Reflux

coughing, retching, wheezing, vomiting and general pain and discomfort.

ASPIRATION is when the contents of the stomach spill over into the windpipe and into the lungs. This can result in repeated lung infections; something Spike suffered from a lot. It is serious for two reasons: physically, it can damage the lungs and psychologically, it can make a child scared to eat or even refuse to eat at all.

Spike's reflux was worse when he had a cold, during spring when the pollen count was high or when his stomach was distended (and in his case, that was much of the time). He had pH studies and impedance studies to measure his stomach acidity and record how many times he was refluxing over a 24 hour period. He was prescribed various medications to reduce his symptoms: some to speed movement and help his stomach empty and others to lower his stomach acidity. He also had a gatrostomy inserted into his stomach to allow us to manually release trapped wind or give him food and liquid directly without the risk of causing aspiration.

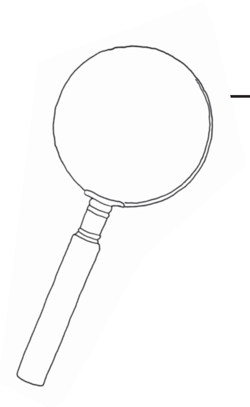
GASTROPARESIS is a condition caused by slow stomach emptying. The longer food sits around, the more gas is produced, the greater the distention and pain. The pressure can also push the diaphragm upwards against the lungs making it harder to breathe.

VOMITING is a response of the stomach to protect itself. If it senses a threat, it contracts to push the offending substance up and out of our mouth. If vomiting becomes chronic, for example on a daily basis, it needs to be investigated.

STOMACH or GASTRIC ULCERS occur when an already inflamed stomach lining is further irritated by stomach acids. Stomach ulcers cause a sharp burning pain 1 to 2 hours after eating. If your child regularly talks of pain after eating, keep a record and see if there is a pattern that can be reported back to your consultant.

FUN FACTS TO SHARE WITH YOUR CHILD

- An adult's gut is an astonishing 7m long – about the same length as a large ambulance!
- Every time we eat, cry or talk, we swallow air. The faster we eat, the more air we swallow, the more we will burp. So SLOW DOWN.
- The stomach can more than double in size to hold food but to avoid discomfort we say: 'Never eat off a plate bigger than your head'.
- We produce and swallow up to 5 cups of spit a day!
- If your vomit looks like soup and makes your mouth burn your food has come from your stomach. If your vomit is slightly green and tastes really awful it has come the whole way from your small intestine.



Notes and Questions

ALONG

THE SMALL INTESTINE

We are now in the small intestine where we will travel through three sections. The first, at the top, is the letter C shaped duodenum, the second mainly on our left hand side is the jejunum and the third, at the bottom and mainly on our right hand side, is the ileum.

The small intestine is perhaps the most important part of the gut. Its job is to extract the maximum amount of nutrients from the food we eat. To do this, it is covered with thousands of tiny finger shaped projections called villi that increase the amount of surface available for digestion and absorption. 90% of absorption takes place here.

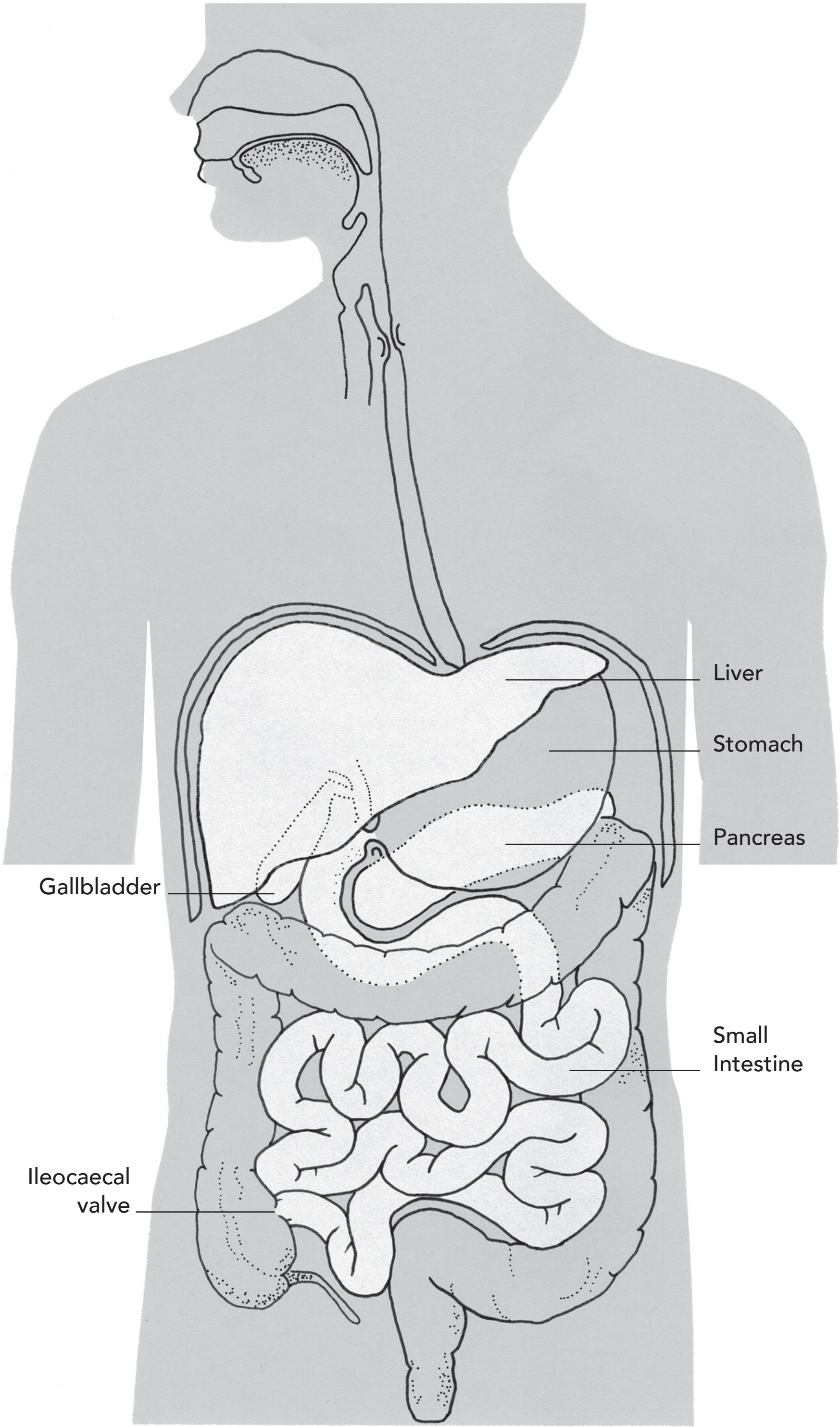
SO HOW DOES IT WORK?

The pancreas, which sits behind the stomach, releases enzymes that digest protein, fat and starch into the duodenum. It also produces the hormones that help regulate our blood sugar level and the hormones that control appetite. The gallbladder sits under the liver. It stores and releases bile into the duodenum to neutralise acid and break down fat.

It takes about 4 hours for peristalisis to move chyme along the whole length of the small intestine. It is pushed backward and forwards in a shuttle motion as nutrients are extracted and absorbed by the blood vessels in the villi. This nutrient rich blood is then carried off to the liver for processing and distribution through our body to provide energy. What is not immediately needed is stored as fat in cells around our body. Some stored fat is essential but of course too much can pose a health risk.

At the bottom of the ileum, the last section of the intestine, there is a ring of muscles called the ileocaecal valve. When the liquid chyme has been reduced to waste and indigestible food (mainly fibre), this valve opens and chyme passes into the large intestine for the last stage of its journey.

An ileostomy is when the ileum is diverted through a hole or stoma on the tummy. This allows poo and gas from the small intestine to pass into an external bag



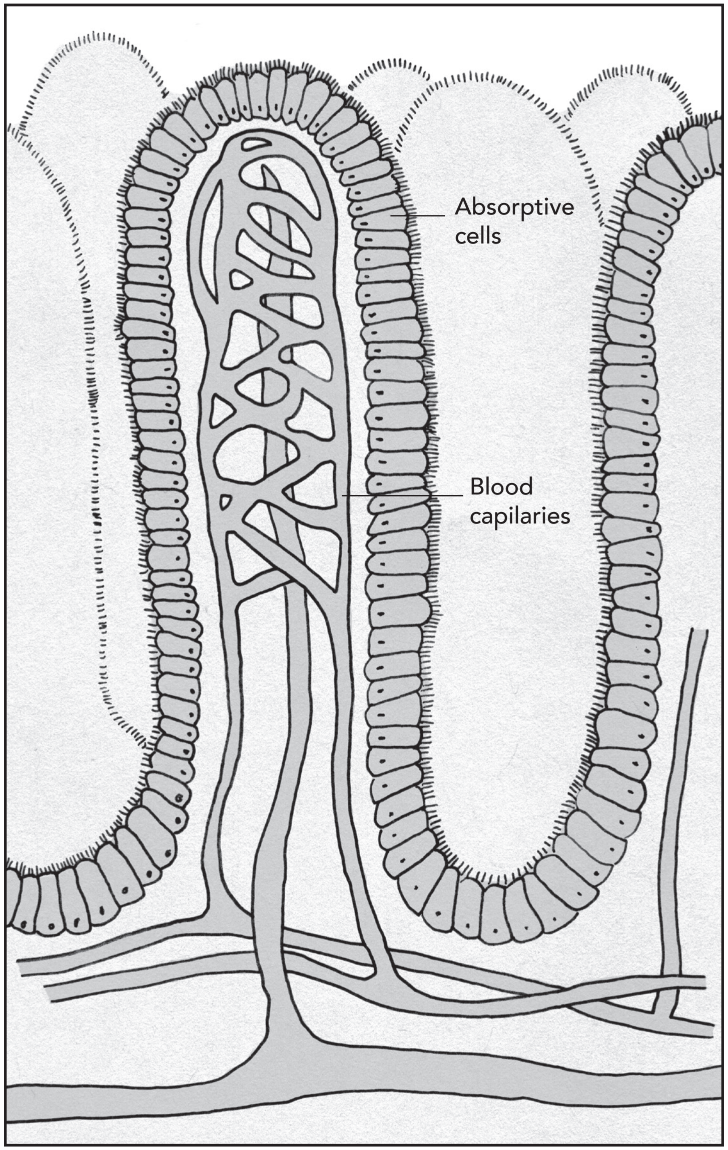
that is emptied regularly. Because of his condition, Spike has an ileostomy. There are advantages to this: air in his bowel can be vented to relieve discomfort or pressure on his lungs and it is easy for us to see the effects of certain foods. We can also prevent dehydration if we notice a lot of liquid in his bag by giving him extra fluid and medication. Having an ileostomy made a huge improvement to his life but it does set him apart from other children.

BUT WHAT CAN GO WRONG?

The most common symptoms of a problem in the small intestine are discomfort, weight loss or dehydration and are usually first treated with feeding changes such as a diet that excludes certain food types or by giving enteral feeds and medication to lower acidity or slow down the passage of food. Where a child is failing to thrive because of intestinal failure, nutrients can be delivered directly into the bloodstream, this is called parenteral nutrition (PN).

Below are some of the conditions that can cause issues in the small intestine:

INFLAMMATORY BOWEL DISEASE (IBD) is a term used to describe inflammation in the gastrointestinal tract. IBD-U is an unclassified irritation or inflammation. Crohn's disease is a type of inflammatory bowel



Picture of villi, the absorptive surface of the small intestine disease that causes inflammation in any part of the gut but most commonly affects the ileum and the large intestine. Ulcerative colitis (UC) is an inflammatory bowel disease that affects the large intestine.

Symptoms can include diarrhoea, constipation, abdominal pain, tiredness, weight loss and blood or mucus in poo.

COELIAC DISEASE is an auto immune condition caused by a reaction to gluten, the sticky dietary protein found in wheat, barley and rye. It causes inflammation in the lining of the small intestine.

Symptoms can include diarrhoea, abdominal pain, tiredness, weight loss and blood or mucus in poo.

A DUODENAL ULCER is caused when the lining that protects the duodenal walls from the acidic partly-digested food breaks down.

Symptoms include pain after eating. If your child complains of discomfort 2 to 4 hours after they have had a meal, try to notice if there is a pattern.

GALLSTONES are pea-sized balls of crystallised bile fluid that can block the passage of liquid bile into the duodenum.

Symptoms include pain, jaundice (a yellowing of the skin and the whites of the eyes) and pale poo. Some children like Spike, have gallstones, which are

managed with medication; others may need to have the stones removed surgically.

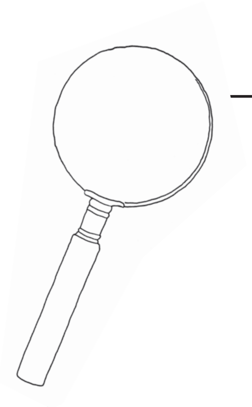
RAPID TRANSIT DIARRHOEA is when food moves through the gut too quickly and the bowel does not have time to properly absorb nutrients.

Symptoms include weight loss, dehydration and diahorrea. There are different causes for this with different types of treatment.

SHORT BOWEL SYNDROME (SBS) is a condition where there is an inability to maintain nutrient, fluid and electrolyte balance because a smaller length of bowel means there is less time for food to be digested. Some children are born with a short bowel and some end up with one because of surgery. Sometimes the bowel adapts and only short term parenteral nutrition (PN) is needed.

FUN FACTS TO SHARE WITH YOUR CHILD

- An adult's small intestine is over 3 metres in length – that's like two pianos end to end.
- Burping is necessary to release air. Some cultures see it as a sign of appreciation! If you are struggling to burp, sit upright and stretch your neck.
- Our digestive system produces approximately 7 litres of fluid a day – that's almost a bucket of fluid!
- The liver is the heaviest organ in our body. An adult liver weighs about 1.5kg and is about the size of a football!
- When we begin to fart after an operation, it means our gut is working again.



Notes and Questions

↓OUT

THE LARGE INTESTINE

We are now on the last stage of our journey. When what is left of the food we eat arrives in the large intestine, its nutrients have largely been absorbed. Even though it will spend 80 to 90% of its time in the large intestine, only 10% of digestion actually happens here.

The large intestine, often called the colon, runs up our right hand side to the bottom of our ribcage, crosses our body and goes down our left side ending at our rectum where poo is pushed out through our bottom (the anus).

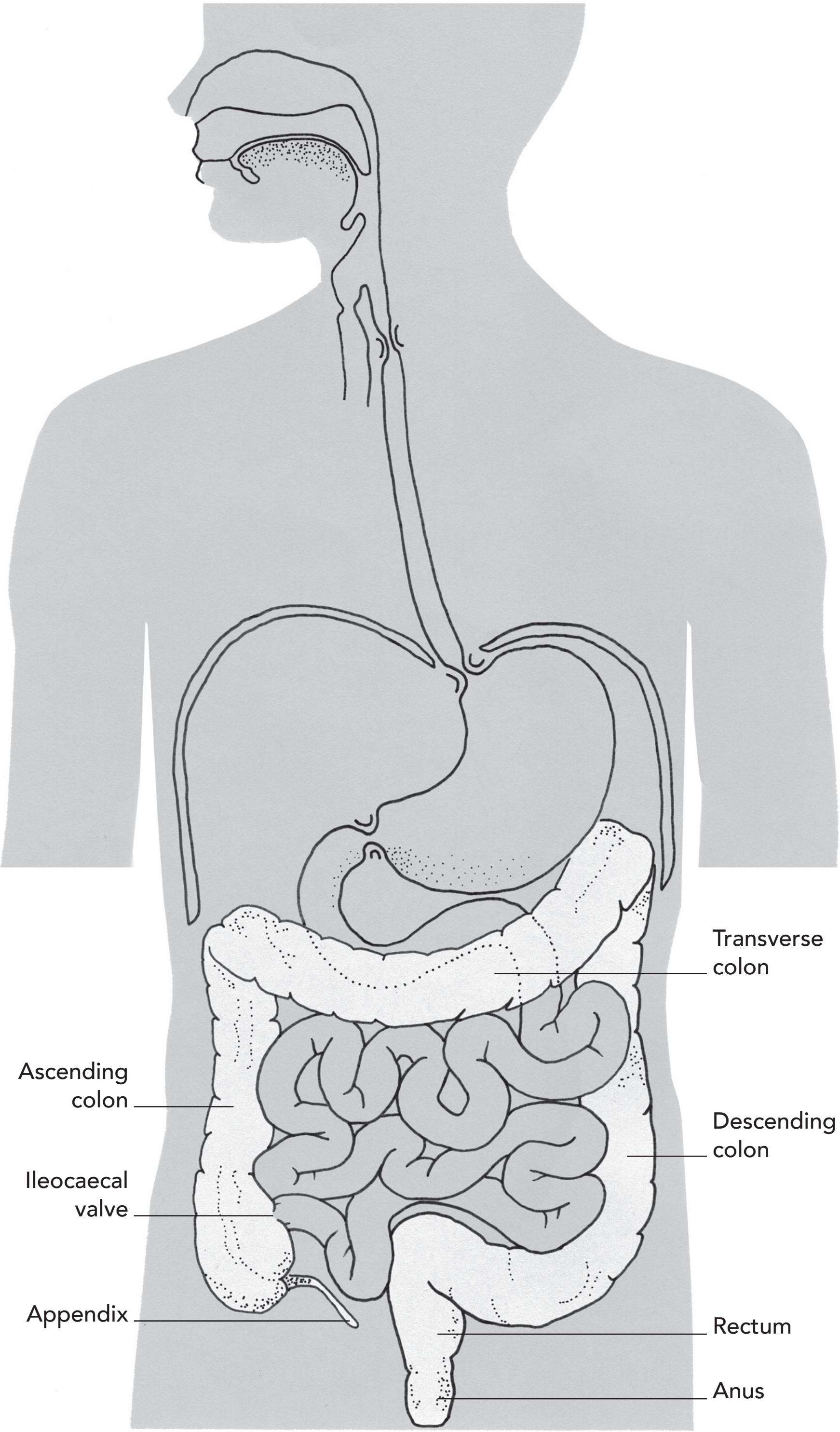
SO HOW DOES IT WORK?

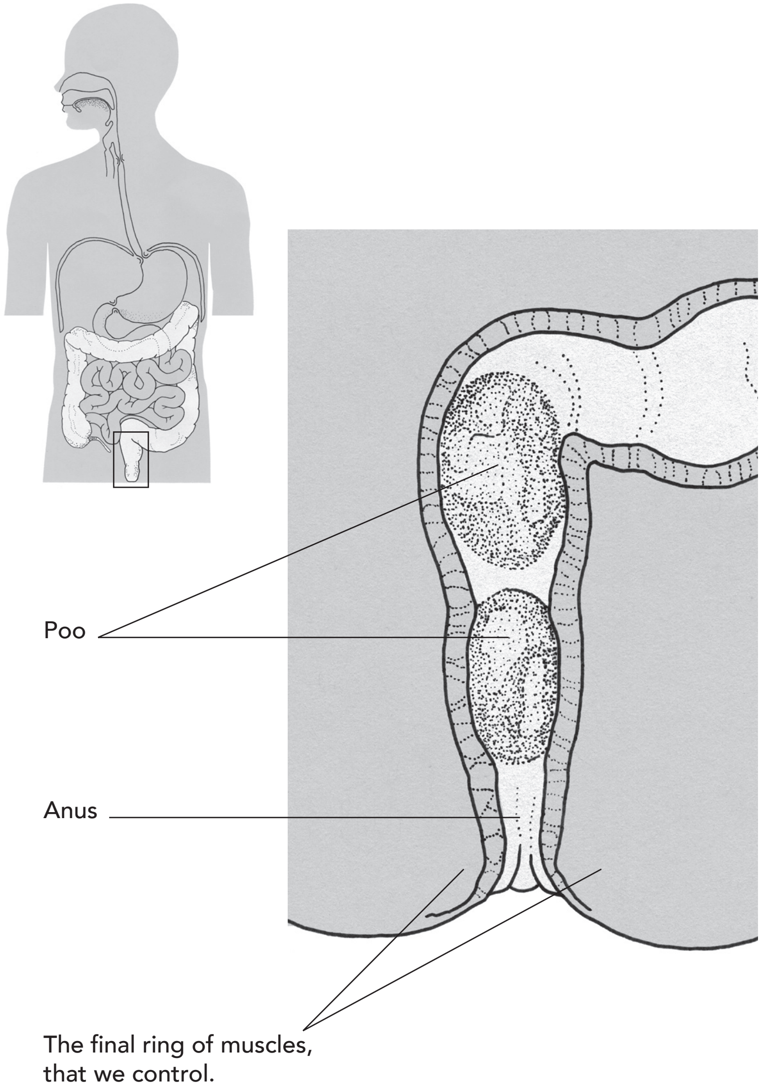
There are 2 types of peristaltic movement in the colon. Shuttle contractions are subtle, they happen all the time and are similar to the forward and back movements in the small intestine. Mass peristalisis is not subtle; eating more food triggers a big contraction that propels the contents of the colon like a wave towards the anus. This is the reason we feel the urge to go to the loo in the morning and after meals.

The colon usually has a natural balance of healthy bacteria (sometimes called flora or probiotics) which protect us from harmful bacteria and contribute to the health of our immune system. They are also essential for the digestion of the dietary fibre remaining in the chyme that has arrived in the colon.

The final fermentation process that takes place between these bacteria and the chyme, happens in our ascending colon: the part that rises up our right side. This digestive process produces vitamin K, many of the B vitamins and lots of gas. The vitamins are absorbed and the remaining food waste and gas moves into the transverse section crossing our body where water, salts and some gas are absorbed. A soft mass of poo is formed and held in the descending section (and the 'S' shaped sigmoid colon) until the big mass peristaltic movement pushes it into the rectum.

When the rectum senses it is full, it triggers a ring of muscles known as the anal sphincter to open, allowing poo to enter our anus. This happens automatically but,





Picture showing poo held in the rectum

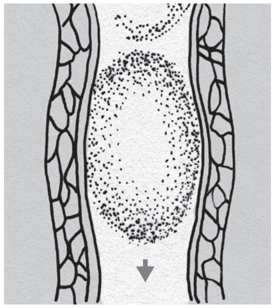
to prevent us from having accidents, we have a final ring of muscles, the external sphincter, that we control. We can choose to poo or to hold – the first time we have had any conscious control of our food since it left our mouth! If we decide to hold, our poo will return to our rectum where it will stay until the next round of peristalsis.

How often people poo varies greatly but as a general rule, we should poo daily or every other day, we should not strain and our poo should look like the images of number 3 or 4 of the Bristol Stool Scale on p44.

That is it! If all has gone well, our food has completed its long journey from our mouth. Hopefully along the way, the nutrients it contained have been extracted and absorbed, creating energy and healthy growth for our body.

BUT WHAT CAN GO WRONG?

FAECAL INCONTINENCE is a condition experienced by those who have little or no control of their external sphincter. In children, this includes all toddlers up to the age of 3, ones who have not yet been potty trained, those born with an abnormality affecting their anus or rectum, those who have a neuromuscular disability and, surprisingly, some who also suffer with constipation (see overleaf).

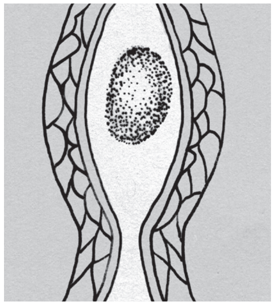


NORMAL

A soft mass of poo stimulates the muscles in the colon wall.

The muscles contract and relax rhythmically to move the poo toward the anus.

Passing the poo is easy.



CONSTIPATION

The longer poo stays inside the colon, the harder and more compact it becomes.

The tired colon struggles to move the dried-out poo along.

It becomes painful to pass.

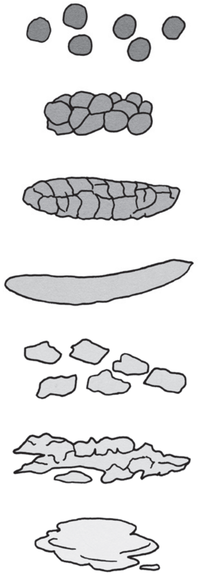
CONSTIPATION, the inability to poo, is very common. In children, it is often the result of holding on to poo or of not allowing enough time on the toilet to fully empty. The poo that remains inside starts to dry, becomes hard and then is painful to pass. This can lead to a cycle of fearing the pain and further holding on.

Over time, residual poo can build up and stretch the colon. When it is stretched, the colon can become tired and struggles to contract to move the dried-out lumps along. Liquid poo from above can then pass through gaps and result in soiling, which is easily confused with diahhorea.

Constipation is usually treated with laxatives. Some bulk out the poo with extra sources of fibre (for example Fybogel/Movicol) – these take several days to work. Some increase the water content in the poo making it softer, larger and easier for the colon to move (for example Lactulose) – these also take several days to work. Others stimulate the muscles and nerves of the gut (for example Senokot/Dulcolax) – these should work overnight. It is also important to increase fluid intake; try to use foods high in fluid such as soup, yoghurt, jelly and fruit.

DIARRHOEA is when food passes through the intestines too quickly for proper absorption, resulting in poo that is watery and difficult to control. The most common cause is a bug or food poisoning. If this is the case, it is best for a child not to eat during the early stages but to sip on fluids and drink dioralyte rehydration salts which replace lost fluids and prevent dehydration.

Diarrhoea which persists can be the sign of an irritation or inflammation. Because there will not have been enough time for the proper absorption of nutrients, water and salts; this can lead to weight loss, more serious dehydration and general lack of energy. It is now much more important to keep drinking and to see a doctor.



Type 1	Seperate hard lumps, like nuts
Type 2	Sausage-like but lumpy
Type 3	Like a sausage but with cracks in the surface
Type 4	Like a sausage or snake, smooth and soft
Type 5	Soft blobs with clear-cut edges
Type 6	Fluffy pieces with ragged edges, a mushy stool
Type 7	Watery, no solid pieces

Adapted from The Bristol Stool Form Scale

WIND can simply be as a result of the air we swallow when eating or talking but it is usually caused by the gases made during the breakdown of food. Regular and smelly wind is a sign that food has been sitting around in our large intestine for too long; often a sign of constipation. Massaging a child along the direction of the large intestine and getting them to lie on the floor with their bum in the air can help to release the discomfort of both constipation and wind.

To help you poo, raise your knees and lean forwards.

COLON FAILURE happens when the muscles and nerves that co-ordinate the passage of food along the colon fail to work properly and movement slows or even stops, causing an obstruction.

Rectal wash-outs are a temporary manual solution to removing poo and gas from the large intestine. They involve injecting a washout solution into the rectum with an enema, a catheter inserted into the bottom.

For the longer term, there is a surgical procedure called an antegrade colonic enema (ACE). This creates an opening through the stomach wall into the caecum, the first part of the large intestine through which fluid can be inserted to flush poo out of the bottom.

If sections of the colon need to rest as a result of infections, trauma or disease, the colon can be diverted through a hole or stoma in the abdominal wall. This is called a colostomy and is used to extract poo and gas from the large intestine into an external bag that is emptied regularly.

WHY DO DOCTORS ASK US TO LOOK AT POO?

Although it is not what most of us would choose to do, looking at and smelling poo is one of the best ways to assess the health of the digestive system. Keeping a log of a child’s sensations, pains and toilet times as well as the consistency of their poo is a very useful diagnostic tool for their health carers.

A baby’s first poo is black. It is called meconium and is a sign that their digestive system is working.

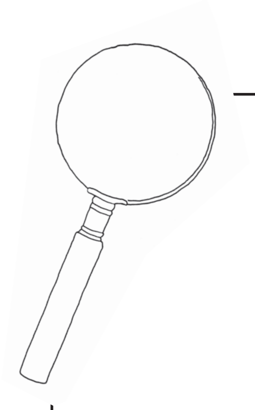
Mucus in poo accompanied by a fever is generally the sign of an infection. If this does not clear within a couple of days, or if it increases and there is blood in the poo, you should seek medical advice.

Poo floats usually because it is full of trapped air. A pale, floating, smelly and greasy poo can be a sign that nutrients are not being processed and absorbed properly. If this is an ongoing issue it needs to be reported to your consultant who may recommend dietary changes or order blood and stool tests and prescribe antibiotics for bacterial infections.

Lumpy bits in poo is not a problem, it is just indigestible food like sweetcorn. In fact you can use sweetcorn and beetroot to time how quickly food is moving through your gut!

FUN FACTS TO SHARE WITH YOUR CHILD

- We fart about 12 times a day – some considerably more!
- It can take up to 3 days for each meal to travel through the digestive tract.
- Ever wondered how we know if we need to poo or fart? Our nerves test the contents of our bottom and report back to our brain.
- The liver is our only organ that can re-grow parts of itself and will do so in an amazingly short period of time – 3 to 4 weeks!
- To help you poo blow a kazoo! We use the same muscles for blowing as we do for pooing.



Notes and Questions

AROUND

FOOD FOR THOUGHT

WHY FOOD & FLUID ARE IMPORTANT

It is important to act on the dietary advice you are given, but it is not always easy. Time, expense and what your child will and will not eat can make it really tricky.

Using ready meals and packaged food is appealing but can be much less straightforward than you would imagine. Labels are often confusing and frequently these foods lack some of the essential nutrients a child needs. It can be a lot simpler to stick to fresh food; at least that way you can control what is going in without worrying about the consequences.

Water is vital! We can go for weeks without food but only days without water. Every bodily function, especially digestion, needs water. Water transports nutrients, it flushes away waste and it controls our body temperature. Children do not always recognise the sensation of thirst so regular fluid intake is essential. Fluid intake can also be increased by foods like soup, jelly and yoghurt.

By planning meals that include a variety of foods in the correct portion sizes and by drinking 8 – 10 glasses of fluid a day most people will absorb all the nutrients they need.

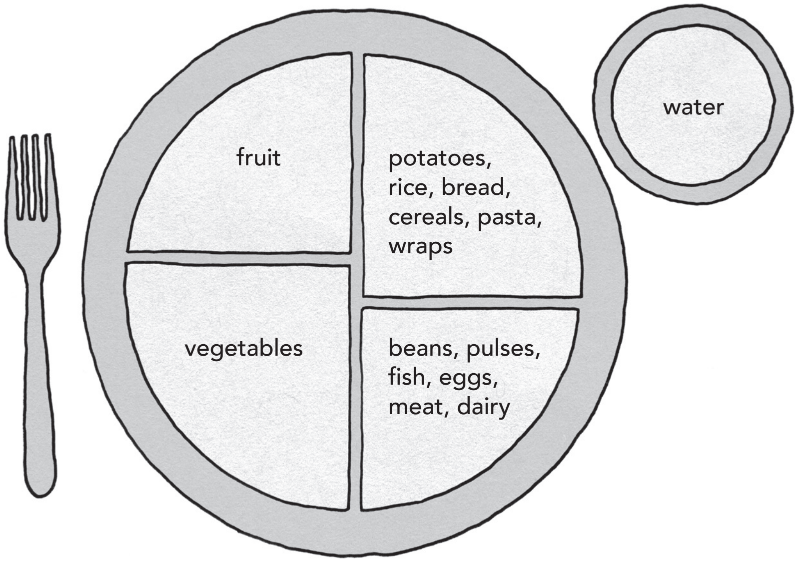
FOOD FACTS & TIPS

Porridge makes for a healthy breakfast. It's cheap, it is a soluble fibre that helps prevent constipation and you can add lots of things to it to make it more appealing to a child – but beware: fibre without fluid stays hard so drink an extra glass of water!

Lunch is not going to be converted into energy until mid-afternoon or early evening so a child may need regular nutritious snacks to maintain a continual supply of energy.

Fatty and sugary food can stimulate reflux, cramping and diarrhoea.

Reduce wind by cutting back on foods such as broccoli, lentils, raisins, onions, bagels and beans.



Aim to eat a variety of food in these proportions

Probiotics are good bacteria that help to restore the natural balance of the gut. They are available in live yoghurt and fermented vegetables such as sauerkraut and miso. We give Spike a probiotic supplement.

PROCEDURES

They can be horrible but generally they are worth it.

Spike has had so many operations that our family has become quite used to them. We have found things that help us, but everyone copes in their own way. There is no right or wrong.

There are lots and lots of procedures linked to gastroenterology, many of which are listed below, but what is very useful to know, and took me years to find out, are the kind of resources that support you and your child when they need a procedure. Here are some you may find useful.

Play specialists can be seen on the childrens' wards. They are great at distracting kids who are bored, anxious or in discomfort by getting them involved in craft activities and games.

Clinical psychologists can support children and parents with difficulties, such as worries or fears, that may arise from having a gastroenterology condition. They also work with parents when a child has difficulties feeding.

The hospital school is an amazing resource if your child is missing a lot of school. As well as some educational support it normalises some parts of the day by giving children company, distraction and fun with activities such as storytelling and games.

Getting to know the many amazing people who work in these areas and on the wards can make your hospital visits become a much more positive experience. It has done for us.

Procedures during which your child stays awake and you are with them are fairly straightforward but when surgery is involved and a child is put under anaesthetic, it can be very frightening. Handing your child over to a medical team involves an act of faith and giving up control; you will not be in the theatre with them or know what is going on, possibly for many hours. Spike developed a very strong phobia for needles and an almost sixth sense for when he was about to be sedated. This makes having procedures extremely stressful as he becomes possessed by an extraordinary strength and struggles to escape.

Getting to know the surgical team if your child is having an operation can make a big difference. Your surgeon, the person who leads the operation, and the anaesthetist who puts your child to sleep, are generally very busy so it is a good idea to write down any questions you have before you see them. If possible, try to make sure they give you time before (so that you and your child understand exactly what is going to be done) and afterwards (so you can understand how it went and what will happen next).

You can always speak to your nurse and ask if there is a play specialist or psychologist available to support your child during this time.

TYPES OF PROCEDURES

ALLERGY TESTS are made with skin pricks to see if a child is at risk from a particular substance (an allergen). A drop of the allergen will be put on the skin and a small prick made at the spot. If there is an allergy, the skin will react. This does not particularly hurt but can be scary if a child is afraid of needles as Spike is.

ANTEGRADE COLONIC ENEMA (ACE) is a stoma on the abdomen through which fluid can be injected via a catheter to wash poo out of the bottom. An ACE tends to be used when there are abnormalities affecting the anus and rectum, when there are nerve problems in the gut or for chronic constipation.

BIOPSIES are when small areas of tissue are surgically taken from the body and investigated under a microscope for diagnostic purposes. They are performed under anaesthetic.

BLOOD TESTS give a doctor information about how the body and organs are working and help them come up with a treatment plan. A nurse will look at your child's hands, wrist and the inside of their elbow to find a suitable vein. They will then apply an anaesthetic cream and stick a plaster over the vein. After 20 minutes the cream makes the skin numb so your child will not really feel the prick of the needle. Spike is needle-phobic so blood tests are very problematic and tend to now only happen under sedation.

EGG (electrogastrogram) is a test where sensors are attached to the outside of the tummy to record movement in the stomach muscles. This does not hurt and needs no sedation.

ENDOSCOPIES are performed under anaesthesia. There are various types: gastroscopies, video capsule endoscopies/colonoscopies. Your Gastroenterologist will pass a thin, soft tube with a jelly bean sized camera down the mouth or up a child's bottom to look at the lining of gut. By doing so, they will be able to check for inflammation, ulcers and obstructions.

A GASTROSTOMY or PEG is an opening made by surgery through the stomach to which an enteral feeding device can be attached. It is used when a child cannot eat or eat enough to meet their nutritional needs.

A MANOMETRY TEST measures how well the muscles and nerves of the different areas of the gut are working. There are various types: anorectal, antroduodenal, colonic, or oesophageal. Your child will be sedated whilst tubes are inserted in a way that is similar to the impedance study but your child will be awake during the test (which can last anything from an hour to a day). Again, take DVDs and anything that may help distract your child!

MRI & CT scans are painless but are often done under sedation as they can be intimidating and a child may need to stay still for quite a long time. An older child may be able to stay awake and watch TV or a DVD. I advise taking a favourite film with you as a distraction. The scanner is a giant tube like a huge toilet roll into which the bed slides. These scans give a much more detailed picture of the gut than an ultrasound.

NASO GASTRIC TUBE (NG) is a method of feeding that bypasses the oesophagus using a soft tube passed down the nose and into the stomach. It is also used to vent the stomach. The technique of inserting it is sometimes taught to parents to do at home.

NASO JEJUNAL TUBE (NJ) is a method of feeding that bypasses the stomach using a soft tube passed down the nose through your stomach and into the jejunum.

NISSENS FUNDOPLICATION is an operation to strengthen the top of the stomach to prevent chronic vomiting and the aspiration and lung infections that it can cause.

PH/IMPEDANCE STUDIES measure the movement and frequency of liquid and air up and down the oesophagus. A thin, soft tube is passed down the nose and into the lower end of the oesophagus. To confirm that the tube is in the correct position, an x-ray is taken. Then the tube will be attached to the child's face with a plaster, wrapped behind the ear and passed into a rucksack containing a little portable machine used to record the results. Inserting the tube does not hurt but it is frightening and can feel very unnatural. Sipping on water during the test will help lubricate the back of the throat and prevent irritation.

RECTAL WASHOUTS help to remove poo and gas from the large intestine. They are performed by inserting a tube called a catheter 2 to 4 inches up the bottom and flushing in a saline solution or water using a large syringe. This is not very nice for anyone involved, but was the only solution to remove poo for Spike prior to his ileostomy.

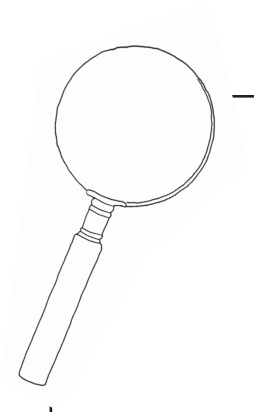
STOMA is a surgical opening made in the abdomen in order to divert the flow of poo or urine. There are various types: ileostomy, colostomy and urostomy. An ileostomy comes from the small intestine, a colostomy from the large intestine and a urostomy drains urine from the kidneys.

TOTAL PARENTERAL NUTRITION (TPN) often just called parenteral nutrition (PN) is a procedure used when the gut needs a rest or if other methods of feeding have been tried and failed. A liquid solution is designed specifically for a particular child to give them all the nutrients needed for growth and development. A catheter or long line (also known as a PICC line or peripherally inserted central venous catheter) is inserted into a vein that leads to the right hand side of the heart and to which a pump can be fixed. If TPN is needed for the long-term, this pump is held in place by a Hickman or Proviac line. Your child will be sedated during the insertion of the long line.

ULTRASOUND is a painless test that allows doctors to see the size and shape of the gut and the accessory organs (the liver, pancreas, gallbladder) though it cannot tell how well they are working. Your child will be asked to lie on a bed while the radiographer squirts warm gel on their abdomen and touches their skin with a smooth probe that allows them to see inside. You can tell your child that the same procedure was done before they were born so that they could be seen in the tummy!

VIDEOFLUOROSCOPY, barium x-rays and contrast enemas are special types of X-rays that allow a doctor to see how the gut is working. Your child will be asked to drink a special flavoured shake (they get to choose the flavour). The shake contains a substance that will show up on the x-rays. If a child has a gastrostomy, the shake can also be introduced through it. As the liquid moves along the oesophagus, the stomach and the intestine, the radiographer will take a series of images. It can be quite fun watching the screen or, if you prefer, you and your child can watch TV or a film while the procedure takes place. The session can take an hour, sometimes more. After drinking barium, poo will look pale and chalky. There is nothing wrong with this so don’t worry!

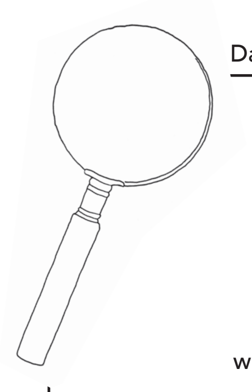
X-RAYS are pictures that are taken by radiographers to help doctors see inside the body – all a child has to do is to stay still.



Notes and Questions

A Digestive Diary

Writing a diary and monitoring gut health is helpful for you and your gastroenterologist. On the following pages you can find templates with the kind of things that are useful to keep a note of.



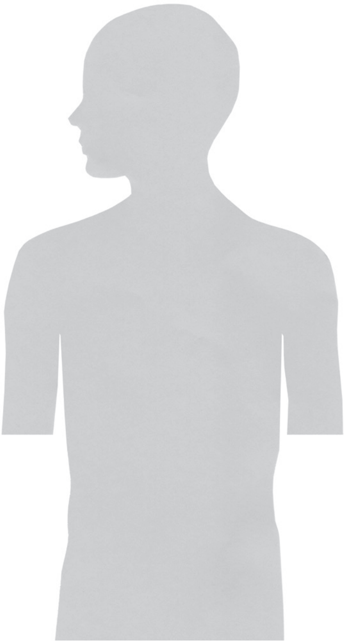
Date:

HOW ARE YOU FEELING TODAY?

Circle a number between 1 and 10
with 1 being completely fine and 10 the most painful

1 2 3 4 5 6 7 8 9 10

Draw on the body where your pain is.
Is it: high up; low down;
near your belly button; on your right;
on your left or in your bottom?



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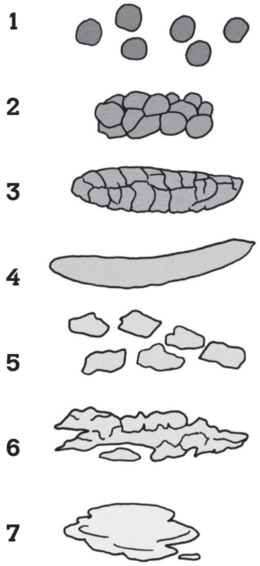
Was it sloppy, hard or in the middle?
Which number on the chart did your poo most look like?

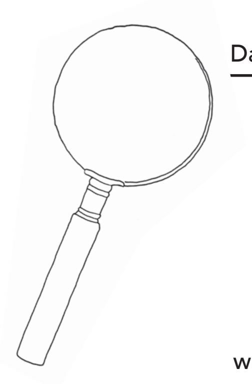
Did you have to run to the loo, strain or was it easy? (circle)

How many times did you go the loo today?

Did you feel better afterwards?



Adapted from The Bristol Stool Form Scale



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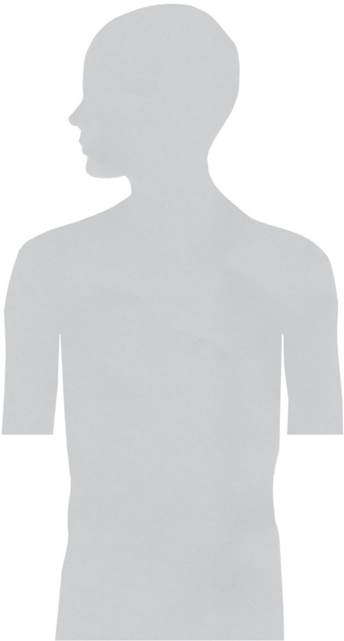

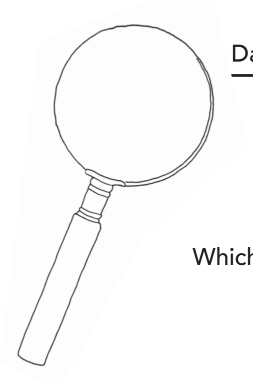

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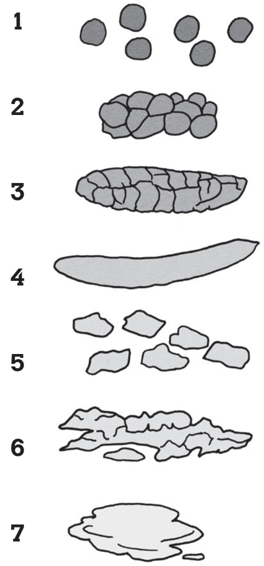

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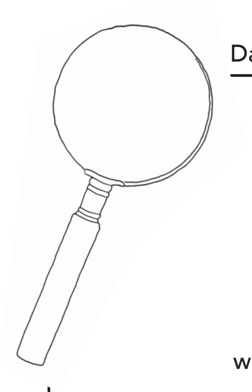

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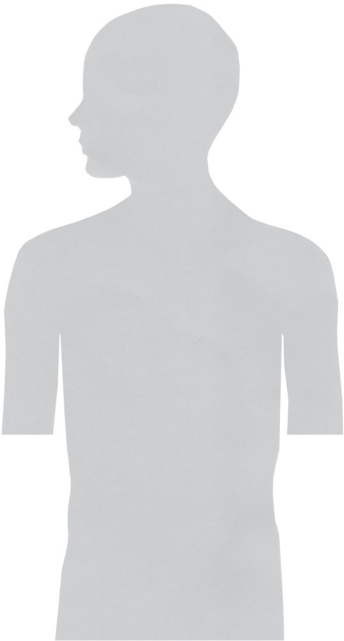

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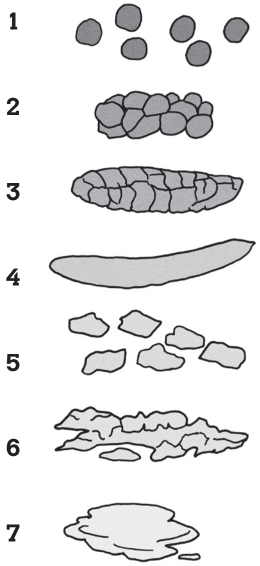

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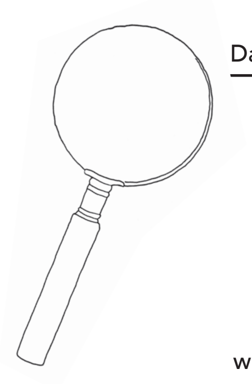

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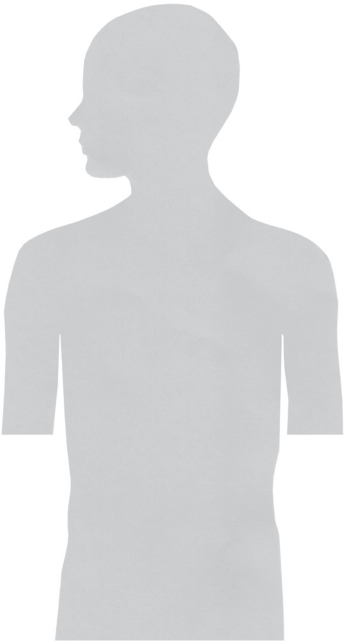

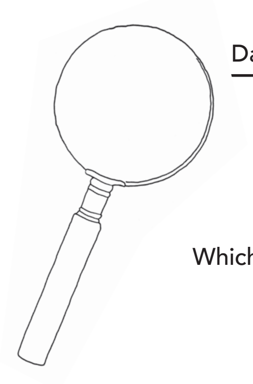

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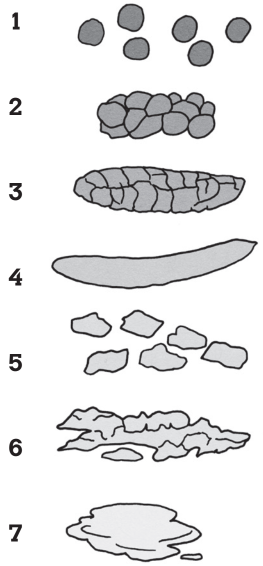

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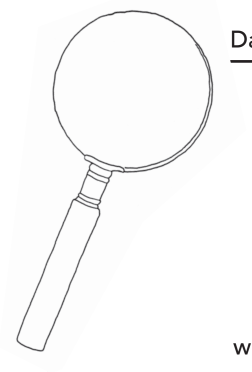

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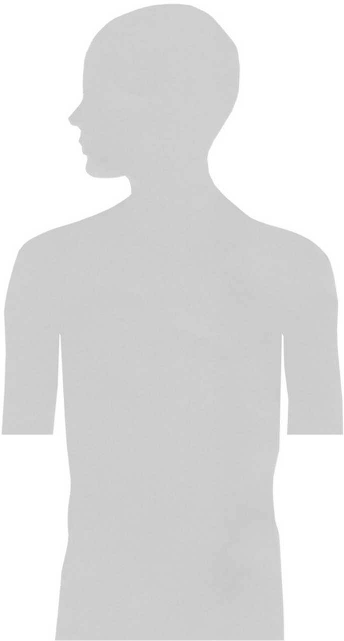

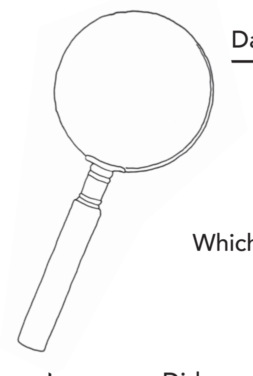

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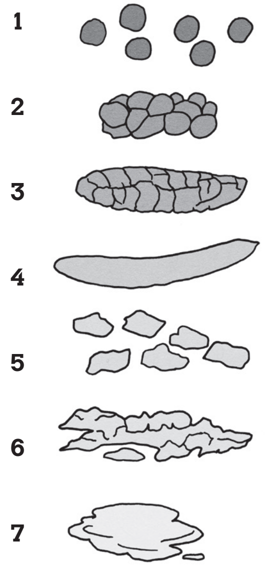

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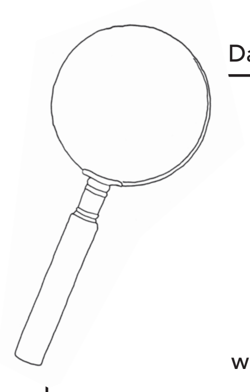

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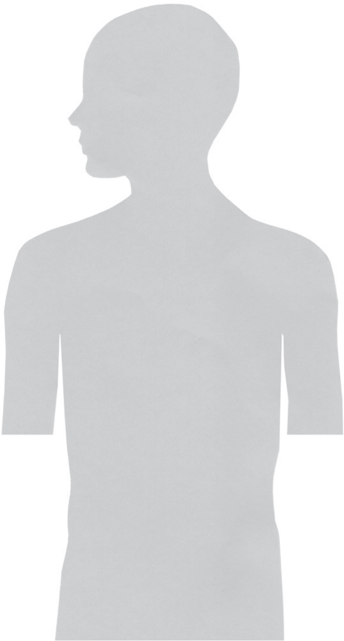

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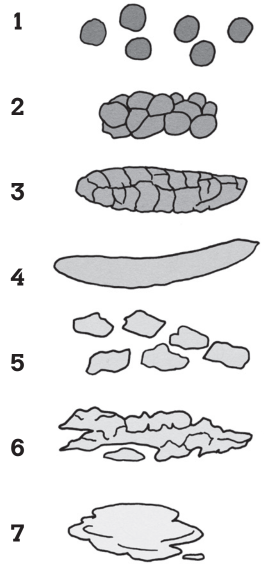

Adapted from The Bristol Stool Form Scale

GLOSSARY

Abdomen – the part of the body that holds our digestive organs.

Allergy – an unusual reaction to a common food or substance.

Amylase – a chemical (enzyme) that digests starchy food.

Anaesthetist – the person who puts your child to sleep before an operation.

Anal Fissure – a tear in the lining of the anal canal (the final segment of the colon).

Anaphylaxis – a severe allergic reaction.

Anus – the end of our digestive tract – our bottom.

Antegrade Colonic Enema – an opening made into the colon through which fluid can be pushed to flush poo out of the bottom.

Aspiration – when food goes down the windpipe and into our lungs.

Barium X-ray – a moving X-ray, like a video (see procedures).

Bile – an alkaline fluid made by the liver and stored in the gallbladder.

Biopsy – the removal of tissue from the body for examination.

Bolus – the lump of food the mouth makes by chewing.

Ceacum – the first part of the large intestine and the location of the appendix.

Chronic – long lasting.

Chronic Intestinal Pseudo-Obstruction (**CIPO**) – a condition where the muscles or nerves that control the movement of food and waste along the gut stop working.

Chyme – partly digested food.

Coeliac Disease – a condition caused by a reaction to gluten.

Colitis – inflammation of the colon.

Colon – the large intestine.

Colonoscopy – an examination of the inside of the colon (see procedures).

Colostomy – an opening made into the colon so that poo can be diverted into a stoma bag on the outside of the tummy (see procedures).

Constipation – infrequent and hard poo or the inability to poo.

Contrast Enema – a form of X-ray (see procedures).

Crohn's Disease – an inflammatory bowel disease, usually in the ileum and large intestine.

CT Scan – detailed X-rays of our insides (see procedures).

Dehydration – when our body is losing more fluid than it is absorbing.

Diaphragm – the muscle that separates the chest from the abdomen.

Diarrhoea – loose and watery poo.

Dioralyte – a supplement with various salts given to help rehydration.

Digestion – the breaking down of food into nutrients.

Distension – a bloating or swelling of our gut.

Duodenum – the top part of the small intestine.

Dysphagia – a difficulty in swallowing or the sensation that food is sticking on our throat.

EGG (electrogastrogram) – a test that records movement in the stomach muscles (see procedures).

Endocrine Gland – a gland such as the pancreas that releases hormones into the blood to support our bodily functions.

Endoscopy – an examination of the inside of the gut (see procedures).

Enteral Nutrition – a nutrient rich liquid diet.

Enteric Nervous System – the nerves responsible for controlling our digestive process.

Enteritis – inflammation of the small intestine.

Enzymes – proteins that stimulate the breakdown of food.

Epiglottis – a flap of tissue that sits beneath the tongue at the back of our throat.

Faecal Incontinence – when there is little or no control over the passing of poo.

Faeces – poo, solids, defecation, stool.

Fibre – the indigestible parts of fruit and vegetables.

Flatulence – wind, gas, flatus, fart.

Gallbladder – the organ that stores bile.

Gallstones – balls of crystallised bile fluid.

Gastroenteritis – an inflammation of the gastrointestinal tract.

Gastroenterologist – a doctor who deals with problems of the gut.

Gastroesophageal Reflux Disease (**GORD**) – a condition that causes contents from the stomach to be forced back up into the oesophagus, throat or mouth.

Gastrointestinal Tract (GI Tract, Intestine or Gut) – a name for the entire system of muscles and nerves from our mouth to our bottom.

Gastroparesis – a condition caused by slow stomach emptying.

Gastrostomy – an opening in the abdomen that allows a child to be tube fed.

Gluten – the sticky protein found in wheat, barley and rye.

Hirschsprung's Disease – a rare condition caused by the absence of nerve cells in sections of the large intestine.

Idiopathic – a condition that has an unknown cause.

Ileocaecal valve – the ring of muscles at the end of the ileum.

Ileum – the final section of the small intestine.

Ileostomy – an opening made into the small intestine so that poo can be diverted into a stoma bag on the outside of the tummy (see procedures).

Impedance Study – a test that measures the movement of liquid and air up and down the food pipe (see procedures).

Imperforate Anus – a partially developed anus or when there is no anal canal.

Inflammatory Bowel Disease – an inflammation in the gastrointestinal tract.

Jaundice – a yellowing of the skin and the whites of the eyes.

Jejunum – the middle section of the small intestine.

Lactose – the sugar found in dairy products, milk, cheese etc.

Larynx – the voice box in our throat.

Laxatives – medicines that prevent or help with constipation.

Liver – an organ that carries out important functions in our metabolism and digestion.

Lower Oesophageal Sphincter (**LOS**) – a ring of muscles at the junction of the oesophagus and the stomach.

Malnutrition – the result of not getting all the nutrients we need from food.

Manometry – a test that measures how well the muscles and nerves of our gut are working (see procedures).

Meconium – a baby's first poo.

Metabolism – the chemical reactions in our body that convert nutrients from food into energy.

Metabolic Disorder – a problem with the way our bodies metabolise nutrients for example, diabetes or vitamin deficiency.

Motility – the movement of food through our digestive system.

MRI Scan – a detailed X-ray of our insides (see procedures).

Naso-Gastric tube (**NG**) – a soft tube that is passed down the nose and into the stomach. Used to vent air and to give enteral feeds.

Naso-Jejunal tube (**NJ**) – a soft tube passed down the nose and into the jejunum. Used to vent air and to give enteral feeds.

Necrotizing Enterocolitis (**NEC**) – a condition when tissue in a baby's gut becomes inflamed and starts to die.

Nissens Fundoplication – a procedure that tightens the top of the stomach to prevent reflux.

Oesophagus – the tube that carries food from our throat to the stomach. Also known as the gullet or food pipe.

Pancreas – an organ that helps with digestion.

Parenteral Nutrition (**PN**) – when calories and nutrients are injected directly into a vein.

PEG – an opening in the abdomen that allows a child to be tube fed enterally.

Peristalsis – the movement of food through our digestive tract caused by muscles.

Peritonitis – an acute inflammation caused by a leaky colon or a ruptured appendix.

pH – a measure of how acid or alkaline something is.

Pharynx – the throat.

Probiotics – the good bacteria that help restore a natural balance in our gut.

Proctitis – an inflammation of the rectum.

Pyloric Stenosis – when the muscles separating the stomach and small intestine become too narrow.

Pylorus – the ring of muscles between the stomach and the small intestine.

Rectal Washouts – a way to manually remove poo and gas from the colon (see procedures).

Rectum – the last section of the colon.

Reflux – a condition similar to vomiting when food travels back up the food pipe into the mouth.

Retching – involuntary vomiting.

Short Bowel Syndrome – an inability to get proper nutrition from food because of a shortened bowel.

Sigmoid Colon – the S shaped bend in the colon just before the rectum.

Sphincter – a ring of muscles that can open and close.

Stoma – an opening in the abdomen to divert the flow of poo into a bag such as a colostomy or Ileostomy.

Suppositories – laxatives that are inserted into the bottom.

Total Parenteral Nutrition (**TPN**) – when a liquid solution of calories and nutrition are given into a vein.

Trachea – the windpipe.

Twisted Bowel – a twist or loop in the gut that causes an obstruction.

Ulcerative Colitis – an inflammation and ulceration of the lining of the large intestine.

Ultrasound – a test to check the size and shape of the gut and its accessory organs (see procedures).

Urinary Sodium Test – a test to detect the level of sodium in the urine.

Videofluoroscopy – an X-ray test that allows a doctor to see how the gut is working (see procedures).

Villi – the lining of the small intestine.

X-ray – a test to make a photograph of the inside of the body (see procedures).

ACKNOWLEDGEMENTS

I would like to thank the gastroenterology and psychology services at Evelina London Children's Hospital, part of Guy's and St Thomas' NHS Foundation Trust. They have cared for Spike with such attention and kindness and have encouraged me to write *Gut Feeling*.

Thank you to Guy's & St Thomas' Charity for making the production of this book possible.

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Gut Feeling is not intended to constitute medical advice. If you have any questions regarding your child's condition you should consult your medical team.

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To find out more about Evelina London Children's Hospital visit www.evelinalondon.nhs.uk