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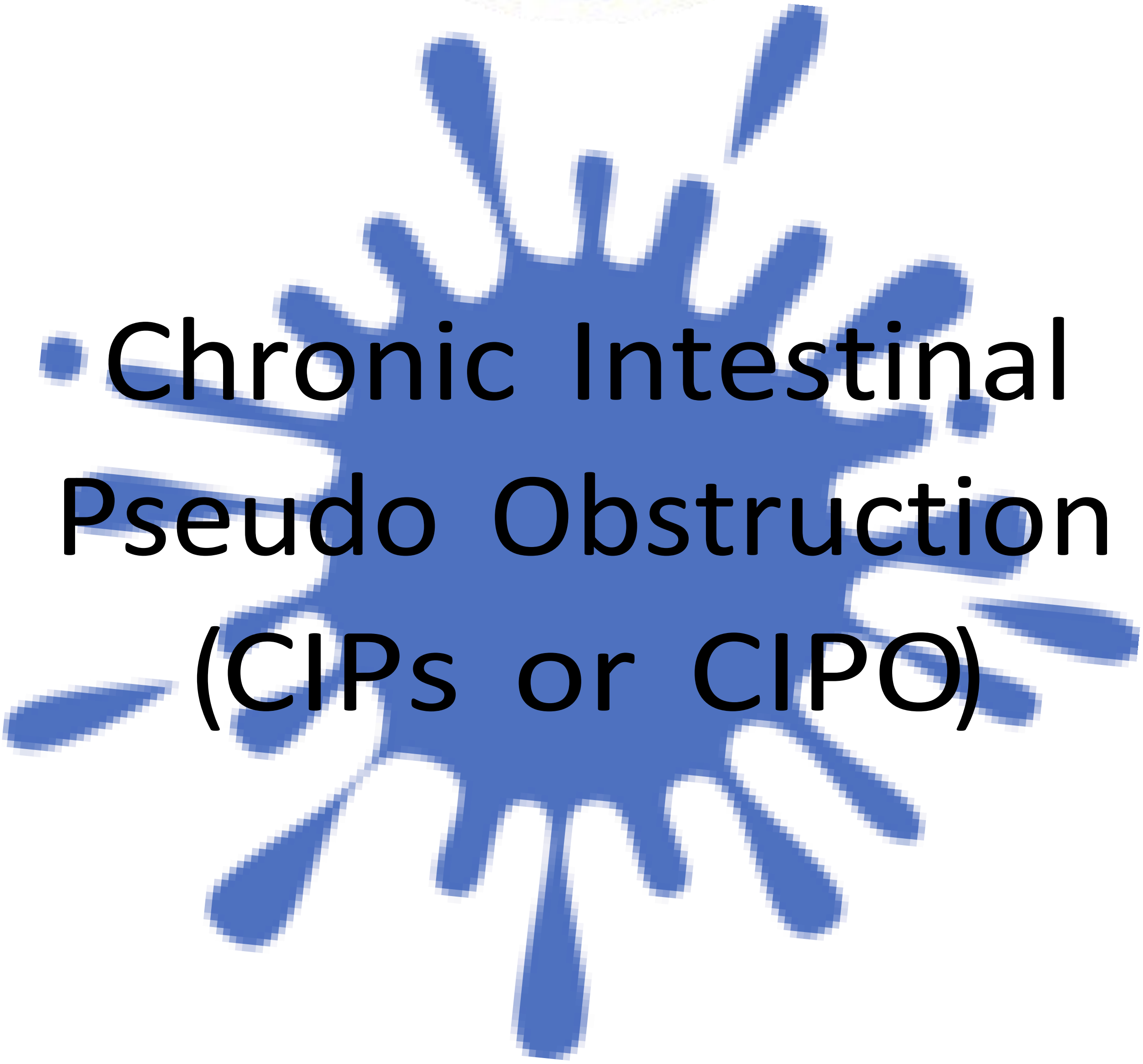


Chronic Intestinal Pseudo Obstruction (CIPs or CIPO)

Information Booklet

Contents:

Glossary

Aseptic - free from contamination by bacteria and viruses (sterile)

Biopsy - taking a small section of tissue which can then be looked at under a microscope

Colon - the large bowel, where stool is formed and water is absorbed. It connects from the small bowel to the rectum

Distension - also known as bloating

Dysphagia - trouble swallowing

Enteral - via the gut

Gastroenterologist - a doctor specialising in gastrointestinal (digestive system) conditions

Gastrointestinal tract - the whole of the digestive system is a tract which is connected from mouth to anus, also known as the gut or alimentary canal

Haemoglobin - the oxygen-carrying substance of red blood cells

Intravenous - into the vein (thus into the bloodstream)

Jejunum - middle section of the small bowel

Malabsorption - a problem with or lack of absorption of some or all nutrients from food

Motility - the movement of the gut and the food, fluid and air through it

Pancreas - an organ which secretes digestive enzymes and produces insulin which allows sugar to get into the cells to be used for energy

Parenteral - not through the mouth or gut

Reflux - where gastric or bowel contents move up the digestive system the wrong way, as in gastro-oesophageal reflux where stomach contents and acid go back up into the oesophagus

Sepsis - the whole-body response to an infection, which can be and often is fatal

Sphincter - a muscle ring which surrounds the gut in various places such as the top of the stomach, bottom of the stomach and anus

Visceral - to do with the internal organs

What is Chronic Intestinal Pseudo Obstruction?

Chronic Intestinal Pseudo Obstruction (CIPO/CIPs) is a disorder of the digestive system known as a motility disorder, whereby the nerves and/or muscles in the gut don’t work properly so the movement of food, fluid and air through the gut is disordered or absent. Although it usually affects the small intestine and large bowel, some people may experience difficulties linked to their oesophagus and/or stomach. The term “pseudo-obstruction” is used to describe the disorder because patients have symptoms normally associated with an obstruction somewhere in the digestive tract and yet no physical blockage is present. The bladder can also be affected.

Symptoms can be very similar to other conditions such as irritable bowel syndrome, colon cancer and inflammatory bowel disease, as the symptoms can be nonspecific and as a result many patients can be misdiagnosed.

In healthy people, from mouth to anus the muscles work together in coordinated movements (peristalsis) to propel food and fluid down through the digestive tract. The digestive system breaks down nutrients into parts small enough for the body to absorb and use for energy, growth and cell repair. The first stage of digestion starts off in the mouth, the jaw and tongue work together to mechanically break down the food by chewing and the contents is mixed with saliva, produced by the salivary glands, which contain enzymes that start to chemically break the food down. The food is then moved to the back of the mouth ready to swallow. Once the swallow is triggered, the tongue pushes the food into the throat. A small flap of tissue, called the epiglottis, folds over the windpipe to prevent choking, and the food passes into the oesophagus. The brain signals the muscles of the oesophagus and peristalsis begins. When food reaches the end of the oesophagus, a ring like muscle, the lower oesophageal sphincter, relaxes and allows food to pass into the stomach (this sphincter normally stays closed to prevent backflow from the stomach).

After food enters the stomach, the stomach muscles mix the food and liquid with digestive juices (hydrochloric acid, enzymes and other gastric juices). The stomach muscles contract periodically, churning food to enhance digestion, and then slowly empty the contents (over a period of 2 ½ to 4 ½ hours) called chyme, into the small intestine. Then the pyloric sphincter (a band of smooth muscle that connects the stomach and small intestine) opens and the partially digested food and stomach juices are pushed into the small bowel.

The small intestine is where most chemical digestion takes place. The contraction of circular and longitudinal muscle of the small intestine mixes the partially digested food, or chyme, with digestive juices from the pancreas, liver and intestine, and moves it along the gut. Most of the digestive enzymes in the small intestine are secreted by the pancreas (in pancreatic juice) and enter the small intestine via the pancreatic duct. The liver produces bile and releases it to the small bowel (duodenum) and the gallbladder primarily stores, concentrates and releases bile; bile breaks down fats.

Certain types of food start being absorbed in the stomach in small amounts, but most of the absorption of nutrition takes place in the small bowel. This means that the digested food molecules pass through the wall of the small intestine into the bloodstream. They are then carried around the body to where they are needed.

A sphincter muscle, the ileocecal value, situated at the junction of the ileum (last portion of small bowel) and the colon, opens and the indigestible material passes into the colon, where water and other key nutrients are absorbed, solidifying it to form stool. Peristalsis is continuous and progressive, pushing the waste material towards the end of the digestive tract. The descending colon stores faeces that will eventually be emptied into the rectum and passed out through the anus.

However, in Chronic Intestinal Pseudo Obstruction, any number of these processes can be affected. As the nerves and/or muscles are affected, causing inefficient or absent motility (movement), these processes don't work. The nerves don't always send the right messages to the muscles, meaning the food isn't propelled because the muscles aren't activated and given the message to push the food through, and/or the muscles themselves are too weak or have wasted away, meaning there isn't the muscle strength to propel the food through the gut. This causes numerous debilitating symptoms.

What are the symptoms of Chronic Intestinal Pseudo Obstruction?

Symptoms include:

- Abdominal pain
- Abdominal distention
- Nausea
- High volume vomiting
- Severe constipation and/or diarrhoea
- Bladder problems including urine retention, frequent urinary tract infections and incontinence
- In some cases, dysphagia (trouble swallowing)

This can result in patients becoming under-nourished because the bowel is unable to digest or absorb sufficient nutrients, or because eating is restricted to avoid unpleasant symptoms after food.

Causes of Chronic Intestinal Pseudo Obstruction

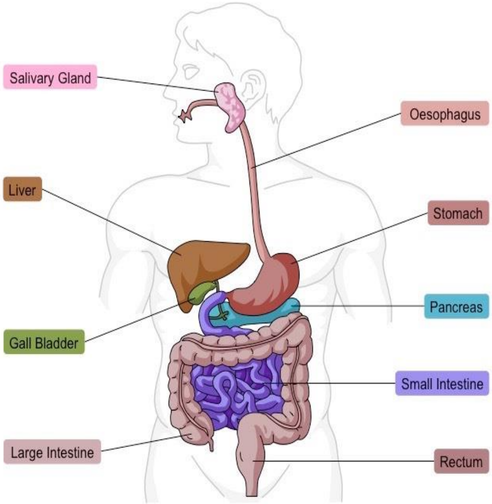
Chronic Intestinal Pseudo Obstruction is a condition in its own right. It is caused by a problem with the nerves and/or muscles of the (the) small and large bowel, but it can affect other areas from mouth to anus including the stomach and oesophagus, and even the swallowing muscles. CIPs arising in the nerves is neuropathic and, in the muscles, myopathic.

CIPs can however be caused by a number of conditions and events/ surgeries:

- Connective tissue disorders/diseases such as Ehlers-Danlos Syndrome, Systemic Lupus Erythematosus and Scleroderma
- Conditions which can or do affect the nerves and muscles such as Parkinson’s, Hirschsprung’s Disease and uncontrolled Diabetes
- Inflammatory Bowel Diseases including Crohn’s Disease
- Mitochondrial Diseases
- Abdominal or pelvic surgery
- Infections

A condition called visceral hypersensitivity (visceral hyperalgesia) can also arise in CIPs where the gut nerves are hypersensitive and register pain constantly, from normal sensations, or from things that should not normally cause pain in the gut.

Chronic Intestinal Pseudo Obstruction gets its name from the symptoms resembling a bowel obstruction, but no obstruction is present, so it is a “pseudo-obstruction”.



Diagnosing Chronic Intestinal Pseudo Obstruction

Numerous tests can be used to diagnosed Chronic Intestinal Pseudo Obstruction but no one test can say you definitely have the condition. It is more of a group of tests can suggest the condition along with a medical history and the ruling out of other conditions.

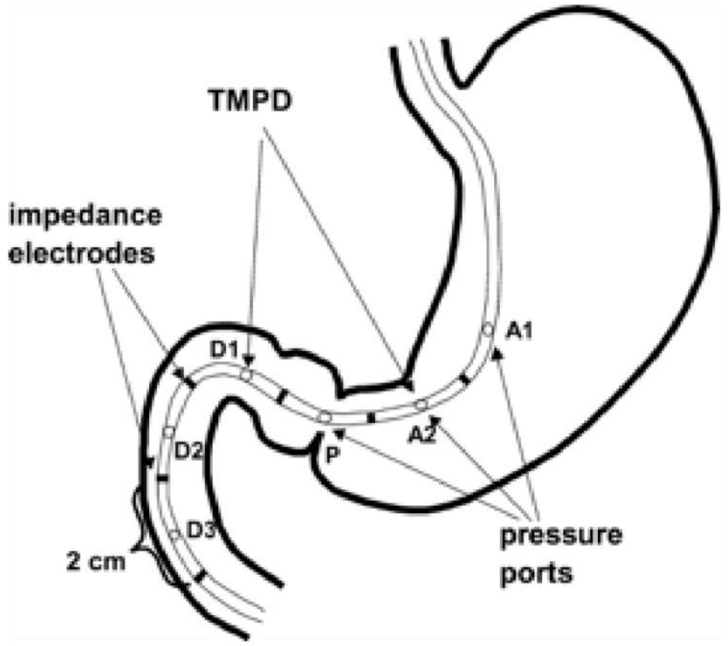
You will be seen by a gastroenterologist, it is always preferable see have one who understands and has an interest in motility conditions, as CIPs is a not well understood and complex illness to diagnose and treat. It's no wonder so many patients don't get diagnosed or get misdiagnosed.

Diagnosis of CIPs includes the key tests which are an antroduodenal (small bowel) manometry and full thickness biopsies, the latter which must be taken in an operation under general anaesthetic. In the manometry, a tube is passed up the nose, down the throat, into the stomach and then through into the small bowel. Here, the sensors in the tube measure contractions in both strength and coordination. You can be awake for this test. In the full thickness biopsies, you will be put to sleep and an incision made so they can access your bowel and take a tiny bit of bowel out, the bit will incorporate every layer of the bowel so that the pathologists can examine each layer of the bowel to understand more about the condition, look at what's going on and also give a diagnosis based on this, in conjunction with other tests.

However, a variety of other tests can be useful in the diagnosis of CIPs, even if only to rule out other conditions. These all assess the condition or function of different parts of the digestive system; they indicate what other areas of the digestive system are affected and possibly see why. These include: endoscopies to look inside the digestive system, usually to rule out other conditions (a gastroscopy or colonoscopy), electrogastrogram to measure the contractions in the stomach, PH probe to measure the acid in the stomach and also test for gastro-oesophageal reflux, oesophageal manometry to measure the contractions of the oesophagus, barium swallow or videofluoroscopy (VFS) to look at the swallowing process to check for any problems such as aspiration (inhaling) of food and fluid, barium meal to look for narrowing in the bowel and to see how quickly things move through, barium follow through to look at the function of the colon and anorectal manometry to look at the function of the last part of the colon, the rectum and anal sphincter, and the sitzmark study (a colon transit study) to look at how far some beads get through the gut in a certain time frame to look at function and speed of the passage of food and fluid through the gastrointestinal tract. This is not an exhaustive list. Blood tests can be useful to look for nutritional deficiencies and anaemia as a result of the gut problems, as nutritional problems are extremely common in CIPs.

One must also be tested for Small Intestine Bacterial Overgrowth which is a state in which there is too much bad bacteria in the gut, causing symptoms such as malabsorption, diarrhoea and weight loss. It is imperative this is treated as it worsens the complications of CIPs - with nutritional problems a common consequence of CIPs, patients can't afford to have malabsorption on top of the functional and absorption problems CIPS patients already struggle with. SIBO is diagnosed by taking a sample of fluid from the gut to look at the bacteria levels, but a breath test can also indicate it. Treatment includes antibiotics (which can be used on a cyclical basis to keep the SIBO under control) and probiotics to introduce more 'good' bacteria into the bowel.

Diagnosis of CIPs means you will need tests that look at the function of the gut - the speed of transit, strength of muscular contractions and the coordination of muscular contractions. Nutrition is a very important part of CIPs, so haemoglobin, vitamin and electrolyte levels also need to be tested and monitored regularly.



Antroduodenal Manometry

Treating Chronic Intestinal Pseudo Obstruction

Chronic Intestinal Pseudo Obstruction is notoriously difficult to treat. There are numerous supportive medications, surgical options and even transplant if all options have been exhausted. Treatment also involves nutritional support, in mild cases a change to the FODMAP or other diet can help, in moderate cases feeding into the stomach or small bowel, and in severe cases feeding directly into the bloodstream, known as Total Parenteral Nutrition or TPN, for when the gut cannot absorb enough nutrition from tube feeds.

Drug treatments

Medications called prokinetics can help speed up the passage of food through the gut. Prokinetic (also called Gastrokinetic) drugs include Domperidone, Erythromycin, Metoclopramide, Prucalopride (Resolor), Linaclotide (Linzess), Mirtazapine and Tegaserod (list not exhaustive). These drugs speed up the contractions of the gut to propel food through quicker.

There are drugs to help relieve constipation such as Movicol and Lactulose and other drugs including Bisacodyl, Senokot, Glycerin suppositories, Sodium Picosulphate, Sodium Phosphate, Ducosate, Magnesium Citrate and Magnesium Hydroxide. Constipation relief involves oral or gastric/jejunal tube solutions and tablets which pass through the gut, drawing water into the stool to make it softer and easier to pass, drugs to stimulate the gut to contract harder and faster, and enemas to wash the bowel out and suppositories to stimulate the bowel via the rectum.

Also common are symptom-relieving drugs such as antiemetics (antisickness) such as Cyclizine, Metoclopramide, Ondansetron and Prochlorperazine, antispasmodics to reduce spasms, such as Buscopan, and painkillers. However, some painkillers can drastically worsen symptoms, as they slow the gut down, in particular opioid painkillers such as Morphine, Fentanyl, Oxycodone and Tramadol. Painkillers that may be helpful and do not have this effect on motility include Paracetamol (usually oral or intravenous), as well as tricyclic antidepressants such Amitriptyline, and anticonvulsants such as Gabapentin and Pregabalin (commonly used to treat neuropathic pain).

Treatment aims to reduce symptoms and improve the movement and function of the gut. Sufferers will most likely be on a combination of different drugs. There is no magic pill, what works for some people doesn’t work for others, and it’s a case of trial and error to find the right drugs and the right combination to reduce symptoms and improve your gut function.

Surgical management

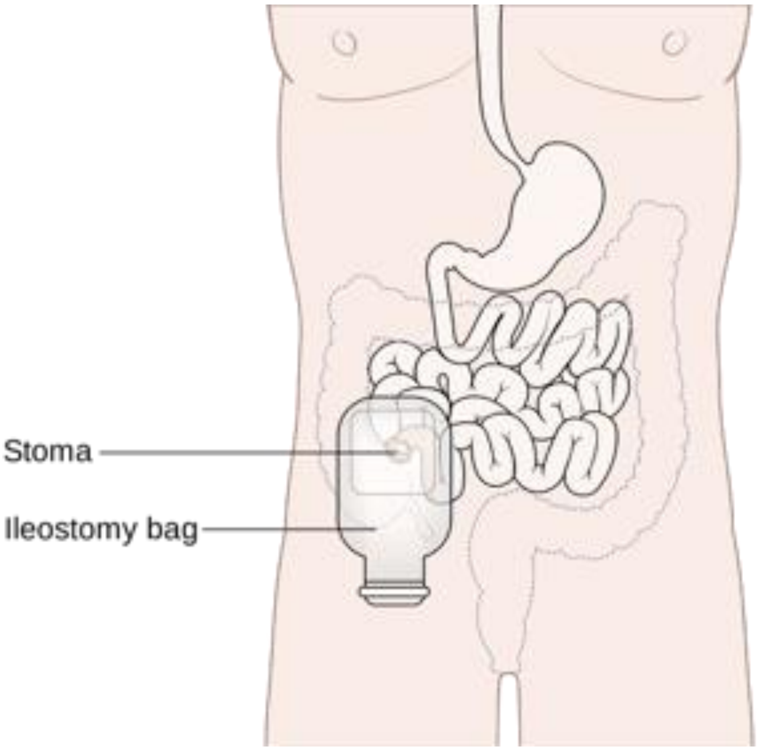
In addition to the medication aspects of managing CIPs, there are also surgical options. These should be a last resort, as surgery can also worsen the condition, but some procedures greatly benefit the patient and improve quality of life.

The most common surgical procedure is the placement of a feeding tube into the stomach or small bowel, which can be done surgically, endoscopically or radiologically. The placement of these tubes allows the patients complete nutrition to be delivered into the stomach or small bowel or for feeds to be used to supplement oral intake. There are various types of tubes but the most common are a Gastrostomy tube or “PEG” which goes through the abdomen into the stomach, the Jejunostomy tube or “Jej” which goes directly into the small bowel, and there is a third combined tube called a PEG/J in which a tube goes through the abdominal wall into the stomach, and then through this tube a second tube is threaded which is then pushed through the stomach and into the small bowel, giving access to both the stomach and small bowel through one hole in the abdomen or “stoma” as the hole is called. In patients who have developed complete intestinal failure, a central line (commonly a tunnelled Hickman line for long-term TPN, or a port-a-cath (PORT)) must be placed. These lines go into a central vein, commonly in the neck, one end is tunnelled out onto the chest lower down to where you access the line, and the other end at the tip sits just above or just inside the heart. These are normally placed in interventional radiology under a local or general anaesthetic. Another use for a Gastrostomy tube is to drain and decompress the stomach, releasing built up gas and acid, and, as is common in CIPs, bile that has refluxed up from the small bowel into the stomach. This can prevent or ease nausea and vomiting.

The other most common surgical procedures are the formation of a Colostomy or Ileostomy, more commonly the latter in CIPs, whereby the colon (in a Colostomy) or small bowel (in an Ileostomy) is brought out onto the surface of the abdomen to form a stoma and a bag is worn over this to collect waste. This bypasses sections of the bowel and decompresses and easily empties the bowel when motility is poor or absent. They serve to improve quality of life, but can also improve the function of the gut and the tolerance of food or liquid/tube feeds.

In CIPs where only a small portion of the bowel is affected, cutting out the affected section of bowel (known as a resection) can improve or completely cure the condition, or if a narrowing has formed in the bowel or a blockage has occurred then a bowel resection will improve symptoms or even save the patients life. One example of this is removing the colon (colectomy) when an Ileostomy is formed, though on many occasions the colon is left in and just bypassed with the Ileostomy.

Another surgical procedure is stimulators including the Sacral Nerve Stimulator for large bowel and rectal dysfunction or for those with gastric involvement, though the success rate is not so high, a gastric pacemaker is an option. The Sacral Nerve Stimulator is implanted under the skin and is attached to the nerves in the lower portion of the spinal cord to stimulate colonic/rectal function. This can make it possible or easier to go to the toilet as the nerves in the spine are stimulated which in turn stimulate the nerves in the bowel to move stool through. This can negate or reduce the need for oral/enteral/enema laxatives and bowel stimulants. The Gastric Pacemaker is implanted in the abdomen and the leads connected to the stomach muscles. An electric pulse is then sent down these wires which stimulate the nerves and muscles in the stomach wall to help it to contract and move food through. It helps with digestion and thus absorption of food, eases nausea and reduces or even prevents vomiting. Both can improve the function of the gut but also improve symptoms and quality of life.



Nutrition in Chronic Intestinal Pseudo Obstruction

Nutritional problems are extremely common in CIPs. With the bowel, and often the rest of the digestive system, not working properly, it is hardly surprising that many of us have to use other means of getting adequate nutrition. There are a few ways of getting this, as will be explained below.

Diet

Sometimes people with mild CIPs can manage with a restricted diet, such as a gluten free, dairy free or other free-from diets depending on the food groups or components that exacerbate symptoms in people which can be a very individual thing, there is no one-size-fits-all approach. There is also something called the FODMAP diet, which works very well for a certain group of people with CIPs though some people find the diet restrictive and hard to follow. FODMAPs are types of carbohydrates found in certain foods. These short chain carbohydrates are resistant to digestion, reaching the far end of the intestine instead of being absorbed. Gut bacteria use them for fuel producing hydrogen gas and causing digestive symptoms in sensitive individuals. Studies have shown strong links between FODMAPs and digestive symptoms like gas, bloating, stomach pain, diarrhea and constipation. The diet cuts out groups of foods containing these FODMAPs, eliminating them from the diet when followed strictly, or customising the diet to suit the individual, using the principals of the diet.

FODMAPs include:

- Fructose (fruits, honey, high fructose corn syrup (HFCS), etc)
- Lactose (dairy)
- Fructans (wheat, garlic, onion, inulin etc.)
- Galactans (legumes such as beans, lentils, soybeans, etc)
- Polyols (sweeteners containing isomalt, mannitol, sorbitol, xylitol, stone fruits such as avocado, apricots, cherries, nectarines, peaches, plums, etc)

However, solids can be harder to tolerate and digest and so another option is a liquid diet. A liquid diet can ease symptoms and at the same time allow the individual to get enough nutrition.

Fortified nutritional drinks

Or for those who aren’t able to get in enough nutrition from a general liquid diet, there are fortified nutritional drinks and other products such as fortified milkshakes, soups and yoghurts. These are specially made with all the nutrients needed to get all your nutritional needs met and to prevent deficiencies. The amount of these drinks you need in a day depends on your individual requirements, any deficiencies you may have and your level of activity. Many patients find sipping these over a period or over the course of the day rather than drinking in one go can help them to tolerate them better.

Enteral/tube feeding

In many patients with Pseudo Obstruction, eating normally or drinking fortified nutritional drinks does not sustain them or is not tolerated. In this instance, tube feeding is the next step.

The nutritional milk feeds can be much like the fortified drinks, whereby all the nutrients are supplied in a special milk which is pumped into the stomach or bowel and then digested, if the bowel can digest the feeds, or it can be a special pre-digested milk known as an elemental feed which, as it’s already broken down, all the bowel has to do is absorb the nutrients from it. This can be crucial in more severe cases of CIPs.

There are a variety of different tubes through which these feeds can be delivered, some of which I will list below.

Nasogastric/Nasal Gastric or “NG” tube is a tube which goes up through the nose, down the throat and into the stomach. A nutritional milk feed is then pumped into this tube and into the stomach.

Gastrostomy or “PEG” *(other types of this include a RIG or a Button)* is a tube which goes directly into the stomach via the abdominal wall. A nutritional milk feed is then delivered through this tube into the stomach, bypassing the mouth and oesophagus.

Nasojejunal/Nasal Jejunal or “NJ” tube is a tube which goes up the nose, down into the throat and through the stomach into the middle section of the small bowel, which is the Jejunum. Feed is then pumped directly into the small bowel, bypassing the stomach, and many patients manage very well on this.

Jejunostomy or "Jej" tube is a tube which goes into the Jejunum (middle section of the small bowel) directly through the abdomen through a hole which is made. Feeds are then pumped through this tube and into the bowel

PEG/J tube is a combined tube which is similar to a PEG, but through the PEG a tube is threaded which extends into the small bowel, giving access to both the stomach and jejunum.

Parenteral (intravenous) nutrition

Total Parenteral Nutrition, abbreviated TPN, is an intravenous (into the bloodstream) artificial feed which is used to bypass the digestive system completely in patients with intestinal failure. This is only used when all other options have been exhausted as it comes with potentially life-threatening risks including infections in the central lines it is delivered through and liver failure, amongst other complications. It is delivered through a central line, forms of these include a:

Hickman Line (also a Broviac or Groshong), a line in the chest which is tunnelled under the skin, with a cuff under the skin near the exit site, and enters the vein usually in the neck, and the tip of it sits just inside the heart or a large vein leading to the heart.

PICC line, a line which enters a large vein in the arm and the tip sits in the same place as a Hickman line, in a large vein leading to or sitting just inside the heart.

Port-a-cath, a special line which is implanted under the skin and accesses a vein in the chest. You do not have an external line when not connected to anything which is great for people who are active, want to swim and don't want the line dangling when not in use. When you want to use the port, you must access it with a special needle.

TPN is a sterile mixture of electrolytes, glucose, amino acids, lipids (fats), essential vitamins, minerals and trace elements in water delivered directly into the bloodstream via a line in a central vein as it is too harsh for small, peripheral veins. The nutrition completely bypasses the digestive system so for those whose guts cannot tolerate, digest and absorb nutrition this is their only option. It's necessary in intestinal failure patients and many patients with CIPs have, or end up with, intestinal failure and thus rely on TPN. It may also be referred to as HPN (Home Parenteral Nutrition) or IVN (intravenous nutrition) The lines it's delivered through must be accessed under aseptic (sterile) conditions as should any germs get into the line, they will go directly into the bloodstream and be pumped round the body, making the person very poorly. It is especially important since TPN provides the perfect breeding ground in the lines as it can provide the bacteria with lots of sugar and nutrients they need to grow and divide. Patients who get infections in their lines can get very poorly very quickly and can easily develop sepsis so temperature and symptoms of an infection must be monitored very closely.

However, TPN doesn't always work and can damage the liver leading to liver failure, or from the lines repeated life-threatening sepsis, and in this case a small bowel or multivisceral (multi-organ) transplant will be considered.

Small bowel or multivisceral/multi-organ transplant

In patients for whom TPN no longer works or poses a risk to the life of the patient, a transplant may be considered. A small bowel/multivisceral transplant is a complex operation only carried out by a few specialist centres. Unfortunately, transplant is not a cure and comes with many risks. The national rates of survival after first intestinal transplant between 1 April 2009 and 31 March 2019 were 51.4% for adult patients and 61.1% for paediatrics at 5 years post-transplant *(Annual report on Intestine Transplantation 2018/2019. NHS Blood and Transplant)* However, transplants can change lives and can give a quality of life far superior to a life on TPN. Sadly, there are no guarantees and transplants do not last forever. Some patients still require TPN or other forms of artificial feeding, and many still suffer with significant gastric problems. Rejection and infection are two other significant issues, and the immunosuppressant medications, which must be taken for life, can have significant side effects. A small bowel transplant just takes the small bowel and transplants it into the patient. However in a multivisceral transplant, anywhere up to 6 organs can be transplanted including the small bowel along with some or all of the following: the stomach, pancreas, liver and/or colon (large bowel) and in some cases a kidney too, particularly if a second transplant is required, due to the renal toxicity of the anti-rejection drugs. A large range of conditions can lead to one needing a bowel or multivisceral transplant so it is not just CIPs patients who could require one. A small bowel/multivisceral transplant is a huge undertaking with many risks and it doesn't offer a complete cure, more trading one set of problems for a second.

Education and Work with Chronic Intestinal Pseudo Obstruction

For CIPs patients in work and education, there are reasonable adjustments that can be made to help you to continue with your education or to continue to work.

Education

To help children continue with their education, reasonable adjustments can be made. The best way to achieve these is to go for an Individual Education Plan (IEP) or Education, Health and Care Plan (EHC), the latter of which has replaced the Statement of Special Educational Needs.

You will need to speak to the SENCO (Special Educational Needs Coordinator) of your child's school or nursery. They can help you to create an Individual Education Plan to suit your child and tell teachers and assistants about their needs, interests and targets and the actions taken to reach these. These help teachers and support staff to know your child, their needs, their interests, but also how to help them reach targets and what needs to be done.

However, for more complex needs/disabilities, an EHC plan will be necessary to meet their needs. An EHC plan is a legalised document issued by the local authority and covers more support than an IEP can give. With an EHC Plan, you, the SENCO or anyone at the school/nursery, a health professional or doctor can request that the local authority carry out an assessment. They will then assess the needs, you must give as much evidence as possible, and they will make their decision. You can appeal if the plan is turned down.

Support includes a 1-1 support worker, extra time in exams, a modified timetable, rest breaks, use of a scribe or laptop, a sloped writing board to help with posture and make it easier for them to write and even time out for therapies such as physiotherapy, speech and language and psychological support or for older students time out for basic skills.

There is also the option of a personal budget where you can employ your own staff and choose how the money is spent to meet your child's needs best. You may be able to get a personal budget for your child if they have an

Education, Health and Care (EHC) plan or are in the process of getting one. It allows you to have more control of how funding
There are 3 ways you can use your personal budget. You can have:

- direct payments paid into your account - you then buy in and manage services yourself
- an arrangement with your local authority or school where they hold the money for you but you still have control over how it is spent
- third-party arrangements - you choose someone else to manage the money for you

Or you can use a combination of all 3.

These can help your child stay in education. However, some children are too poorly to attend school so need home tuition or can only attend part time and need home tuition to top it up. These services are delivered by the local Children’s Support Services where the school provides the work and CSS teach the child or young person to continue their education. Many children thrive with this 1-1 education and it allows them to succeed at their own pace and takes into account their conditions/disabilities and care needs. Your child’s school (the SENCO) should fill out the paperwork to apply for your child to have home tuition. If not, the local Education Welfare Officer can help.

Work

There is now a duty for employers to make reasonable adjustments for disabled employees. Employers have the duty to adjust procedures and remove barriers you face because of your disability/condition so you can work and apply for jobs in the same way as someone who isn’t disabled. It’s the Equality Act 2001 which calls the duty to make reasonable adjustments.

These include making the building wheelchair friendly (ramps, widened doors, moving furniture and adjusting/lowering light switches, door handles and shelves), features to make it easier for vision/hearing impaired individuals to work, providing a wheelchair accessible desk and other equipment, flexible working hours or working from home and even increased time off to accommodate hospital appointments and therapies, regular rest breaks, longer time in assessments, transferring the person to another department, area or altering the job so that they can continue to work if they become disabled or their condition worsens or extended leave due to their condition or employing a support worker to help them.

Specialist centres and expert consultants

The Royal London Hospital
Adults:
Professor Qasim Aziz, Neurogastroenterologist
Dr Michael Glynn, Gastroenterologist (Nutrition)
Dr Asma Fikree, Gastroenterologist
Professor Charlie Knowles, Colorectal Surgeon

Paediatrics:
Dr Sandhia Naik, Gastroenterologist
Dr Nicholas Croft, Gastroenterologist
Mr. Stewart Cleeve, Paediatric Surgeon

St Mark's (Middlesex, Harrow)
Adults:
Dr Simon Gabe, Consultant in Gastroenterology & Intestinal Rehabilitation
Dr Suzanne Donnelly, Gastroenterologist

Great Ormond Street Hospital (Paediatrics only)
Dr Osvaldo Borrelli, Gastroenterologist
Dr Susan Hill, Gastroenterologist
Dr Fevronia Kiparissi, Gastroenterologist
Dr Jutta Köglmeier, Gastroenterologist
Dr Keith Lindley, Gastroenterologist
Dr Efstratios Saliakellis, Gastroenterologist
Dr Nikhil Thapar, Gastroenterologist (On sabbatical)

Salford Royal Hospital (Manchester)
Adults:
Dr Peter Paine, Gastroenterologist (Clinical Lead)
Dr Simon Lal, Gastroenterologist (Head of Intestinal Failure)

University College London Hospital
Adults:
Professor Anton Emmanuel, Neurogastroenterologist
Dr Farooq Rahman, Gastroenterologist (Intestinal Failure)
Dr Natalia Zarante-Lopez, Gastroenterologist/Honorary Senior Lecturer

Wythenshawe Hospital, Manchester University Foundation Trust (MFT)
Adults:
Professor Peter Whorwell, Gastroenterologist
Dr Richard Jones, Gastroenterologist (Nutrition, Clinical director)

University Hospital, Southampton
Adults
Dr Trevor Smith, Gastroenterologist
Dr Nicholas Coleman, Gastroenterologist, functional and motility disorders
Dr Charlotte Rutter, Gastroenterologist & Intestinal Failure

Paediatrics
Dr Nadeem Ahmad Afzal, Gastroenterologist
Dr Akshay Batra, Gastroenterologist (Intestinal failure and motility disorders)
Dr Robert Mark Beattie, Lead for paediatric gastroenterology and nutrition

Royal Manchester Children's Hospital (Paediatrics only)
Dr Fagbemi, Gastroenterologist
Dr Thomas, Gastroenterologist
Mr. Bowen, Paediatric Surgeon

Manchester Royal Infirmary
Adults:
Dr Richard Hammonds, Gastroenterologist

Newcastle Freeman Hospital
Adults
Dr Nick Thompson, Gastroenterologist (Nutrition)
Dr Chris Mountford, Gastroenterologist (Nutrition)

Western General Hospital, Edinburgh, Scotland
Adults:
Dr Alan Shand, Gastroenterologist (Nutrition)

Addenbrooke's Hospital, Cambridge
Paediatrics
Dr Rob Heuschkel, Gastroenterologist
Dr Camilla Salvestrini, Gastroenterologist
Dr Matthias Zilbauer, Gastroenterologist
Dr Kai Hensel, Gastroenterologist

Small bowel and multi visceral Transplant:

Addenbrooke's Hospital, Cambridge
Adults:
Dr Steve Middleton, Gastroenterologist
Dr Jeremy Woodward, Gastroenterologist
Dr Lisa Sharkey, Gastroenterologist
Dr Dunecan Massey, Gastroenterologist
Mr. Butler, Transplant surgeon
Mr. Neil Russell, Transplant surgeon

Oxford (Churchill) Hospital
Adults
Dr Phillip Allan (Gastroenterologist)
Mr. Srikanth Reddy (Transplant Surgeon)

Birmingham Children's Hospital (Paediatrics only)
Dr Girish Gupte, small bowel/multivisceral transplant

King's College Hospital, London (Paediatrics only)
Professor Nigel Heaton, small bowel/multivisceral transplant

About the
Pseudo Obstruction Research Trust (PORT)

Pseudo Obstruction Research Trust
Reg Charity No. 1114217
www.port-charity.org.uk

The Pseudo Obstruction Research Trust (PORT) was formed in February 2006 to raise funds for research into a complex and little-understood condition called Chronic Intestinal Pseudo Obstruction (CIPO), though may also be abbreviated CIPO). It was formed by Sue Stewart and Sonia Frost, who met in The Royal London Hospital while their daughters received medical care for gastrointestinal conditions, in memory of Sonia's daughter Emily Jasmine who passed away in 2005 from CIPO aged 2.

PORT's mission is to fund research into CIPO, raise public and professional awareness of the condition and improve understanding of and treatment options for CIPO. PORT has funded over £750,000 towards research and equipment. Research projects include, a study which looks at a novel approach to Gastroparesis and nausea, undertaken within the human tissue laboratory, at the National Bowel Research Centre, led by Professor Gareth Sanger. Another study funded by PORT looks at developing neurons and their potential for tissue repair, potentially leading to a therapy, led by Professor Joanne Martin. PORT also arranged for CIPO to be included in the NHS 100,000 Genomes research project for rare disorders.

The charity also provides support to patients and their families, via a Facebook support group, we are open to people messaging, emailing for support and advice. We cannot give medical advice, but we can point you in the right direction. PORT always needs support and people to fundraise, so if you, friends or family wish to fundraise, via a sponsored challenge, an event such as a cake sale, coffee morning, pamper evening etc. or supporting us by making a donation, then this will be greatly appreciated.

Meet the Team

Sue Stewart, Chairperson and Co-Founder

Sue has four daughters, Jessica, Emily, Becky and Olivia, and five grandchildren. Two of her daughters suffer with gut disorders, Becky being diagnosed with CIPO at the age of 14. Olivia has a severe motility disorder. Sue has worked with young children for over 25 years. Sue set up the charity with Sonia in 2006 after they met in The Royal London Hospital, whilst their daughters were receiving treatment. Sue has been recognised for her Charity work attending the Her Majesty the Queens Garden party at Buckingham Palace, along with husband Barry, Sonia and Ian Frost.

Sonia Frost, Trustee and Co-Founder

Sonia is the mother of Samuel and “Angel” Emily and she worked with special needs children for 15 years. Emily Jasmine suffered with CIPO and sadly died from the condition aged two. Sonia herself is now unwell with Ehlers-Danlos Syndrome and Dysmotility so has a double perspective as both a parent and a patient. Sonia and Sue have been close friends since they met in The Royal London Hospital.

Dr Nigel John Meadows MD FRCPCH, Trustee

Nigel has worked as a consultant gastroenterology for 30 years, he established the department at The Royal London Hospital, and for many years has specialised in intestinal dysmotility. A keen supporter of PORT he has seen how the charity has become an important granter of research funds. Nigel is now retired from the NHS but remains active in private practice.

Barry John Stewart, Trustee

Barry has worked in the Investment & Financial Services sector for over 30 years, he has now retired. Barry has assisted Sue for many years, and is now able to now devote more time to raising PORT's profile and fundraising. Over the years Barry has met many sufferers of this debilitating condition and realises the importance of future research to give sufferers a better quality of life.

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Other Trustees include; Ian Frost, Ashlee Johnson, Kilian Fitzsimmons-Wilson, Rebecca Stanier, Louise McAuliffe Roberts, Lesley Carmichael and Rachael Green.

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Our charity patrons are Sean Locke and Zander Fagerson.

Contact details

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Sue Stewart Chairperson

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Pseudo Obstruction Research Trust

Registered charity no. 1114217

www.port-charity.org.uk

Also find us on Facebook, Twitter and Instagram

https://www.facebook.com/groups/34457031656/

https://twitter.com/portcharity

@ port_charity

To donate using our Text Giving Code, just text PORT, with the amount you would like to donate to 70085.

E.g. PORT 5, 10 or 20 to 70085

PORT was formed in memory of

Emily Jasmine Frost 21st March 2003 - 7th May 2005

Her memory is a huge legacy, changing, and saving the lives of sufferers just like her. We also remember all the other lives lost to this debilitating and at times life threatening illness.

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