



Chronic Intestinal Pseudo Obstruction (CIPs or CIPO)

Information Booklet

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#supPORTthecause

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 (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 push food and fluid down through the digestive tract. It starts off in the mouth, the jaw and tongue working together to chew food and then move it to the back of the mouth ready to swallow. Once the swallow is triggered, the tongue and the muscles in the throat propel the food down past the windpipe opening, which closes off when you swallow, and then the oesophagus muscles which are like rings round the oesophagus work in unison to move the food down the gullet towards the stomach. The sphincter muscle at the top of the stomach then opens to allow the food into the stomach, where it is held for 2.5-4.5 hours so that the acid in the stomach can break down the food ready for it to move into the small bowel. Once ready, the pyloric sphincter (ring muscle at the opening between the stomach and small bowel) opens and the broken down food is pushed into the small bowel. Next, the pancreas secretes enzymes to break down the food further and the gall bladder secretes more enzymes and bile to continue to break down the food and now it is ready to be absorbed, though 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. Once the nutrition and goodness has been absorbed from the mixture, now known as chyme,

is moved out of the small bowel and into the colon. Here the fluid is absorbed from the chyme and stool is formed. This moves slowly through the colon until you go to the toilet.

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.

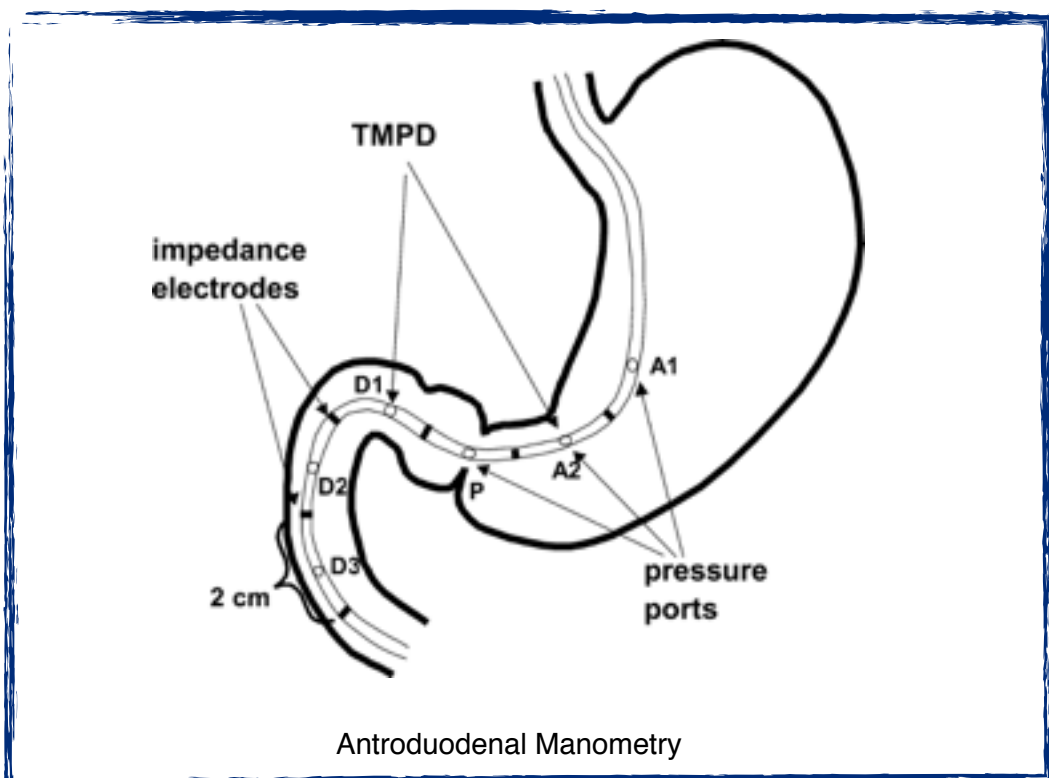
Diagnosis of CIPs includes the key tests which are an antroduodenal (small bowel) manometry and full thickness biopsies, the latter which must be taken in an operation under general anaesthetic. In the manometry, a tube is passed up the nose, down the throat, into the stomach and then through into the 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 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 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.



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, Docusate, 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 (anti-sickness) such as Cyclizine, Metoclopramide, Ondansetron and Prochlorperazine, antispasmodics to reduce spasms, such as Buscopan, and painkillers, however the latter can drastically worsen symptoms as they slow the gut down, especially opioid painkillers such as Morphine, Fentanyl, Oxycodone and Tramadol.

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

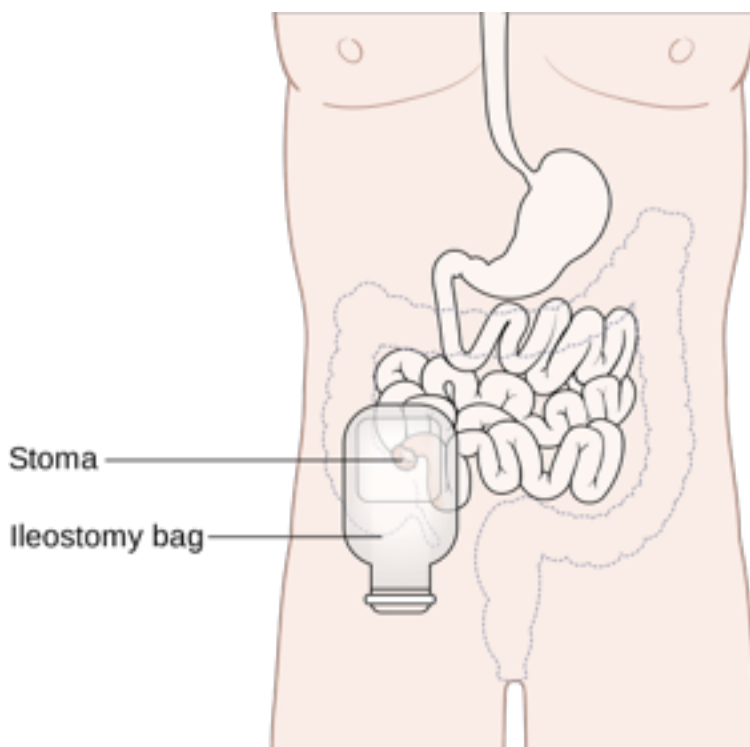
In addition to the medication aspects of managing CIPs, there are also surgical options. These should be a last resort, as surgery can also worsen the condition, but some procedures greatly benefit the patient and improve quality of life.

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) 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 the diet can be very restrictive and hard to follow. It cuts out groups of foods known to worsen or bring on symptoms and eliminates them from the diet when followed strictly, or it can be customised to suit the individual but still using the principals of the diet.

FODMAPs are:

- 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 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.

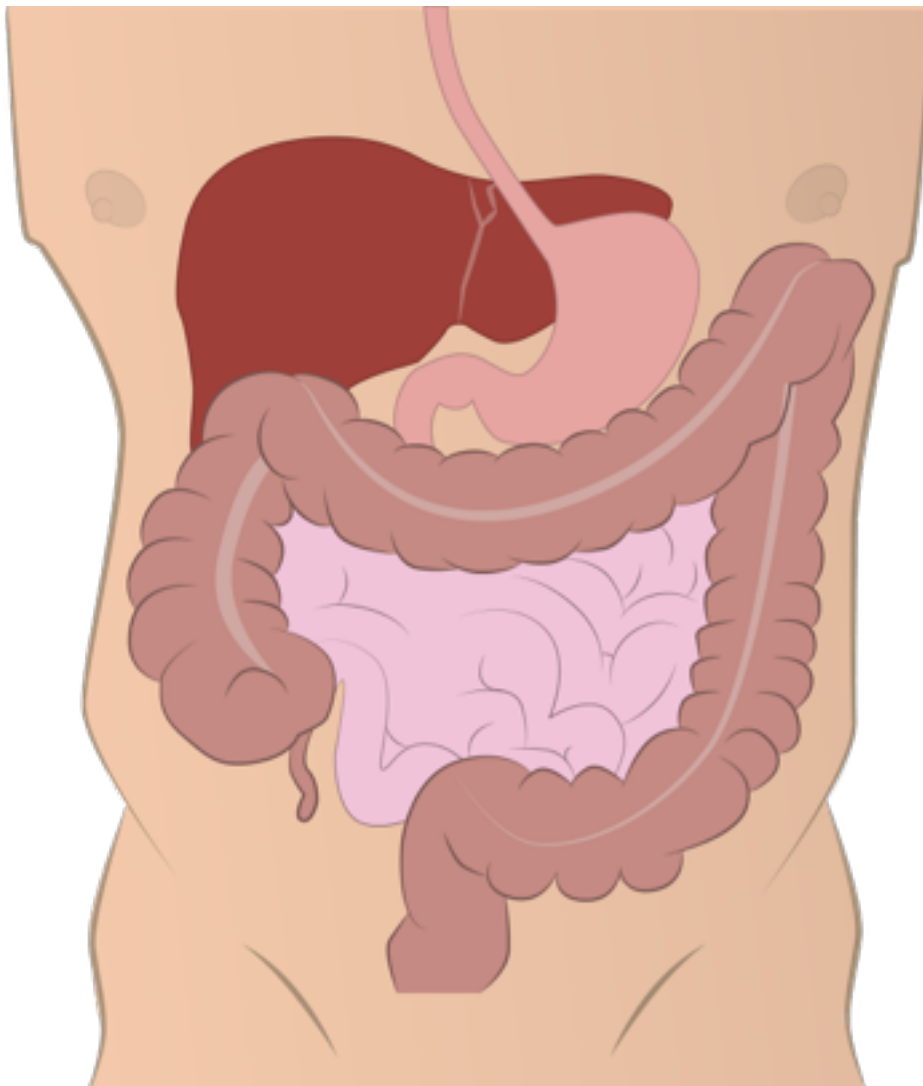
TPN is a sterile mixture of electrolytes, glucose, amino acids, lipids (fats), essential vitamins, minerals and trace elements in water delivered directly into the bloodstream via a line in a central vein as it is too harsh for small, peripheral veins. The nutrition completely bypasses the digestive 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).

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 when 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. It is not a cure unfortunately, and comes with many risks and only a 50% survival rate at 5 years post transplant. However it can change lives and give a quality of life far superior to a life on TPN. A small bowel transplant just takes the small bowel and transplants it into the patient. However in a multivisceral transplant, anywhere up to 5 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). 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, often smaller set of problems post-transplant.



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 Co-ordinator) 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)
Professor Charlie Knowles, Colorectal Surgeon

Paediatrics:

Dr Nigel Meadows, Gastroenterologist
Dr David Rawat, Gastroenterologist

St Mark's (Middlesex)

Adults:

Dr Simon Gabe, Gastroenterologist
Dr Jeremy Nightingale, Gastroenterologist (Nutrition and Intestinal Failure)

Great Ormond Street Hospital (Paediatrics only)

Dr Nikhil Thapar, Gastroenterologist
Dr Lindley, Gastroenterologist
Dr Borelli, Gastroenterologist

Salford Royal Hospital

Adults:

Dr Peter Paine, Gastroenterologist
Dr Simon Lal, Gastroenterologist

University College London Hospital

Adults:

Dr Anton Emmanuel, Gastroenterologist
Dr Farooq Rahman, Gastroenterologist (Intestinal Failure)

University Hospital of South Manchester

Adults:

Professor Peter Whorwell, Gastroenterologist
Dr Richard Jones, Gastroenterologist (Nutrition)

Royal Manchester Children's Hospital

(Paediatrics only)

Dr Fagbemi, Gastroenterologist
Mr Bowen, Paediatric Surgeon

Manchester Royal Infirmary

Adults:

Dr Richard Hammonds, Gastroenterologists

Western General Hospital, Scotland

Adults:

Dr Alan Shand, Gastroenterologist (Nutrition)

Transplant:

Addenbrooke's Hospital, Cambridge

Adults:

Dr Steve Middleton, Gastroenterologist (motility and small bowel transplant)
Dr Jeremy Woodward, Gastroenterologist (nutrition)

Birmingham Children's Hospital

(Paediatrics only)

Dr Giresh 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)



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 (CIPs, 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 CIPs aged 2.

PORT's mission is to fund research into CIPs, raise public and professional awareness of the condition and improve understanding of and treatment options for CIPs. They have raised over £270,000 towards research and have funded projects such as Professor Jo Martin's enzyme defect research and Professor Qasim Aziz's research into the relationship between Ehlers-Danlos Syndrome and CIPs, as well as other research projects at The Royal London Hospital and Great Ormond Street Hospital. The charity also provides support to patients and their families, we offer a Facebook support group and we're always open to people messaging and 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 or your friends/family fancy raising some money, doing a sponsored challenge, organising an event, doing a cake sale, coffee morning or similar, asking your local shop if they'll put a collection tin on their counter or supporting us by making a donation, then this will be greatly appreciated.

Meet the Team



Sue Stewart, Chairperson

Sue has four daughters, Jessica, Emily, Becky and Olivia, and two granddaughters River and Isla. Two of her daughters suffer with gut disorders, Becky being diagnosed with CIPs at the age of 14. Olivia has a severe motility disorder. Sue was a pre-school assistant and had worked with young children for over 20 years. Sue set up the charity with Sonia in 2006 after they met in The Royal London Hospital whilst their daughters were receiving treatment.



Sonia Frost, Trustee

Sonia is the mother of Samuel and “Angel” Emily and she worked with special needs children for 15 years. Emily Jasmine suffered with CIPs 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.



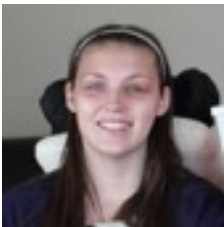
Ian Frost, Trustee

Ian is Sonia’s husband and he is a trained electrical technician. He is a Senior Supervisor at Ford Motor Company where he has worked for over 20 years.



Kilian Fitzsimmons-Wilson, Trustee

Kilian and his wife Lindsey have a son called Charlie who suffers from CIPs. Kilian is a software consultant and spends much of his time presenting software to accountants. A keen rugby player, below average golfer and family man! Living just outside Blackburn, he is keen to raise the profile of PORT and support as the man in the North!



Lucy Watts, Trustee

Lucy is a young person who suffers from CIPs and Ehlers-Danlos Syndrome and secondary intestinal failure. She does a lot of charity work to make a difference and improve care, services, support for unwell and disabled people, raise awareness of the issues they face and awareness of her conditions. Lucy became Trustee of PORT in November 2014. She was announced in July 2015 as one of the Health Service Journal's 50 Patients Leaders for those changing and shaping healthcare.



Ashlee Johnson, Trustee

Ashlee is married to Scott and they have two children, Jack and Isla. Isla suffers from conditions including CIPs and spends a lot of time in hospital. Ashlee and Scott tirelessly raise funds for PORT and awareness of CIPs.

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Also find us on Facebook and Twitter

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

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PORT was formed in memory of

Emily Jasmine Frost

21st March 2003 - 7th May 2005

A much-loved daughter and sister,
Gone but never forgotten.

In her memory there is a huge legacy, changing and
saving the lives of sufferers just like her.



Also in memory of all the other lives lost to this
debilitating and at times life-threatening condition.

www.port-charity.org.uk