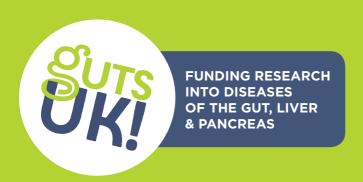
ALL YOU NEED TO KNOW ABOUT

CHRONIC INTESTINAL PSEUDO-OBSTRUCTION





THIS FACTSHEET IS ABOUT CHRONIC INTESTINAL PSEUDO-OBSTRUCTION

Chronic Intestinal Pseudo-obstruction (CIP) is an overall term for several rare conditions which can affect any part of the gut (intestine). Symptoms resemble those caused by a blockage (obstruction) of the gut, but when investigated no blockage is found (hence the term "pseudo"). CIP is caused by an abnormality in the nerves or muscles of the gut, which leads to altered and inefficient contractions (peristalsis) of the digestive tract, so gut content does not pass through properly. When a specific abnormality of the intestinal nerves or muscles is identified, the diagnosis of CIP may be refined to include this. Terms such as visceral myopathy, visceral neuropathy and mesenteric plexitis all fall within the umbrella of CIP.

Contents

WHAT ARE THE CAUSES OF CHRONIC INTESTINAL PSEUDO-OBSTRUCTION?	Page 3
WHAT ARE THE USUAL SYMPTOMS OF CHRONIC INTESTINAL PSEUDO-OBSTRUCTION?	Page 3
HOW IS CHRONIC INTESTINAL PSEUDO-OBSTRUCTION DIAGNOSED?	Page 4
HOW CAN CHRONIC INTESTINAL PSEUDO-OBSTRUCTION AFFECT YOUR LIFE?	Page 4
WHAT TREATMENT IS AVAILABLE FOR CHRONIC INTESTINAL PSEUDO-OBSTRUCTION?	Page 5
DOES CHRONIC INTESTINAL PSEUDO-OBSTRUCTION NEED TO BE MONITORED AND, IF SO, HOW?	Page 6
HOW CAN CHRONIC INTESTINAL PSEUDO-OBSTRUCTION AFFECT YOU OVER TIME?	Page 6
WHAT MORE RESEARCH NEEDS TO BE DONE ON CHRONIC INTESTINAL PSEUDO-OBSTRUCTION?	Page 7

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WHAT ARE THE CAUSES OF CHRONIC INTESTINAL PSEUDO-OBSTRUCTION?

When food is ingested, the gut usually has co-ordinated muscle contractions to help it pass through. However, in CIP this does not happen, the contractions are weak or uncoordinated and gut content does not pass through properly. In the majority of cases, what has caused this damage and weakness to the muscle and/or nerves of the gut is not clear. Occasionally, CIP can be a result of another disease not related to the gut, for example autoimmune conditions such as lupus and rheumatoid arthritis, disorders affecting hormone regulation such as diabetes, underactive thyroid or neurological disorders such as Parkinson's disease. It can also, rarely, be caused by infections such as glandular fever, or following abdominal surgery. Some forms of cancer can cause CIP and, more rarely, it is caused by certain medications such as anti-depressants and opiates. In some cases, it has a genetic component and runs in families. The condition can affect people at any age.

WHAT ARE THE USUAL SYMPTOMS OF CHRONIC INTESTINAL PSEUDO-OBSTRUCTION?

Common symptoms include constipation, nausea, vomiting, bloating of the abdomen and abdominal pain. These symptoms can mimic bowel blockage, so patients are often seen repeatedly in Emergency Departments, and may even undergo surgery before the diagnosis is made. As the disease progresses it can lead to reduced appetite, weight loss and malnutrition. Recurrent bouts of pain can be so severe that morphine-like medications are needed, and these have the frustrating side-effect of making most of the symptoms worse as the intestinal muscle function is further impaired.

HOW IS CHRONIC INTESTINAL PSEUDO-OBSTRUCTION DIAGNOSED?

Investigations may include:

- Abdominal x-ray and a CT scan of the bowel: these will help to rule out
 any mechanical obstruction in the bowel. An MRI of the bowel may also
 be performed and will typically show an enlarged ("dilated") intestine.
 If these scans do not reveal anything unusual then transit studies of the
 gut may be performed to see how content travels through the gut.
- Manometry (pressure studies): these are, rarely, used to measure contractions of the gut.
- Blood tests: these are needed to look for anaemia, infections, hormone levels and antibodies and will also help to establish whether a cause can be found for CIP.
- **Biopsy:** if the results of the above tests are normal, some people may go on to have a small biopsy (tissue sample) of the gut, so the muscles and nerves can be directly visualised and examined. However, this usually involves surgery, which in itself has risks.

It is important to note that although there are various methods of investigating for CIP, in many cases all the results will be normal, making a diagnosis difficult even when CIP is strongly suspected. In many cases the diagnosis is made only after a long delay and despite many unhelpful investigations.

HOW CAN CHRONIC INTESTINAL PSEUDO-OBSTRUCTION AFFECT YOUR LIFE?

- **Symptoms:** CIP can impact on your life via the symptoms it causes such as pain, nausea and vomiting as well as their effects on your general wellbeing due to weight loss and malnutrition.
- Quality of life: CIP can be a long term condition with symptoms that
 occur frequently or are constant. This can badly affect daily activities
 including family, work and social life. It is recognised that recurrent severe
 symptoms with no clear cause can cause major upset, frustration and
 feelings of hopelessness amongst many patients. If you are experiencing
 any of these feeling it is important to let the doctor know, so that
 appropriate support can be organised.

WHAT TREATMENT IS AVAILABLE FOR CHRONIC INTESTINAL PSEUDO-OBSTRUCTION?

The treatment of CIP is usually individual and can be challenging. You may need treatment or support from many different specialists including a gastroenterologist (gut doctor), a dietician, a psychologist and, occasionally, a surgeon. These team members often need to work together to ensure an individualised treatment plan, according to symptoms, age and personal preference. Treatment can include diet changes, nutritional support, medications, decompression of the gut or surgery. If CIP is due to another condition, it is important that the underlying disorder is treated.

- Diet and nutritional support: some people with CIP may become malnourished. This can be potentially life-threatening so it is important that a dietician is involved at an early stage and can advise on certain diets, depending on individual needs. People with CIP are generally advised to eat small meals and often, rather than three large meals a day and to follow a relatively low-fat, low-fibre diet. Fatty foods are thought to delay stomach emptying and high fibre diets tend to cause bloating. If adequate nutrition cannot be maintained through eating food, then other feeding methods may be needed such as NG (nasogastric) or PEG (percutaneous endoscopic gastrostomy) feeding or PN (parenteral nutrition) where feed is delivered directly into a vein.
- Medications: medications are used to help treat symptoms associated with CIP but do not cure it. Prokinetic drugs which aim to improve gut movement by increasing the frequency of contractions can be used. Some examples include domperidone, metoclopramide, erythromycin, octreotide and prucalopride. For nausea, anti-sickness medications can be used. If pain is severe, painkillers can be prescribed. However, it is important to be aware that morphine and morphine derivatives (such as codeine) can make symptoms worse. Low dose anti-depressants and gabapentin can be used to treat chronic pain.

- Decompression: if the gut becomes very large and the patient does not respond to medications, the excess gas may need to be removed in a procedure called decompression. This helps reduce the pressure in the digestive tract. It can be performed using tubes passed into the stomach (through the mouth or nose) or into the bowel (through the rectum, back passage). Some patients gain relief from a large-calibre PEG tube known as a venting peg to allow wind (and sometimes fluid) to pass out from the stomach.
- Surgery: this is reserved for severe cases and rarely performed as CIP normally affects the whole gut. However, if CIP is thought to be limited to one section of the gut, surgery may be used to remove that portion. Extremely rarely, patients may be considered for intestinal transplantation. In general, a key goal is to avoid surgical intervention.

DOES CHRONIC INTESTINAL PSEUDO-OBSTRUCTION NEED TO BE MONITORED AND, IF SO, HOW?

If the symptoms of CIP are well controlled, then regular follow-up with a doctor is not necessary. However, if symptoms are ongoing, regular follow-up is useful to ensure that new treatments for symptom control can be considered and nutrition is monitored. If nutritional support is required, then regular follow-up with a doctor, dietician and/or nutrition nurse is important to monitor weight and ensure the feeding regime is adequate.

HOW CAN CHRONIC INTESTINAL PSEUDO-OBSTRUCTION AFFECT YOU OVER TIME?

For some people with CIP, medications alone may be helpful. However, in general, people with CIP tend to have ongoing symptoms, despite treatment. Sadly, in many cases the condition is progressive and deteriorates with time. However, it is most unusual for CIP itself to prove fatal.

WHAT MORE RESEARCH NEEDS TO BE DONE ON CHRONIC INTESTINAL PSEUDO-OBSTRUCTION?

Unfortunately, there is no cure for CIP. For most patients there are treatments that provide some relief but this is often not complete. CIP is relatively rare and has not received much research interest or funding. Further research into understanding the cause of symptoms is urgently needed to help in the development of new and better treatments. More specific medications or bowel pacemakers, which help to maintain the muscle contractions in the gut, could in the future help to manage symptoms more effectively.

WHAT TO ASK YOUR DOCTOR?



- Has CIP been considered and thoroughly investigated?
- May I be referred to a dietician to see if there are any changes to my diet or supplements I can take?
- What form of pain relief should I take at home to prevent attacks and in hospital when I have an attack?
- Are there any support groups I can join? How often do I need follow-up?

For more information about research in this area please contact Guts UK.

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