Getting to grips with gastroparesis
Frequently asked questions (FAQs)

Please see below answers to some of the commonly asked questions we received during the 'Getting to grips with gastroparesis' online event in September.

We hope this information is useful, informative and answers some of the questions you might have about gastroparesis.

Do you always vomit with gastroparesis?

No, not necessarily. Vomiting is a common symptom of gastroparesis. However, you can feel sick and have upper abdominal discomfort and/or distension (an increase in the size of the tummy), along with symptoms of feeling full quickly and prolonged fullness after meals without being sick. That is why it is difficult to diagnose gastroparesis in many patients.

Is painful bloating due to SIBO (small intestinal bacterial overgrowth) or gastroparesis?

Painful bloating can be present in both conditions. Gastroparesis is often not in insolation, but part of a motility disorder of the whole gut. When the motility disorder affects the small intestine, you often get mid-abdominal bloating.

With SIBO, there are usually small numbers of bacteria in the small bowel and if these numbers increase significantly, they cause symptoms. If someone develops SIBO, there is usually an acute on chronic deterioration of symptoms with pain and loose stools.

Is there any relationship between gut biome and gastroparesis e.g. conditions such as SIBO?

Yes, there is a study that suggests that half of people with gastroparesis might also have SIBO. If people have both conditions, SIBO might be related to small bowel dysmotility. If you think of gastroparesis as part of a more generalised gut motility (movement) disorder, this makes more sense.

I am tube fed into my jejunum for idiopathic gastroparesis. What would cause idiopathic gastroparesis to happen suddenly, with no other obvious reason?

In clinical experience, there are four main groups of people with gastroparesis:

1. People with diabetes.
2. People with hypermobile variant of Ehlers Danlos Syndrome (EDS).
3. People who have had surgery (e.g. Fundoplication, sleeve gastrectomy).
4. The rest (examples are people with connective tissue disorders, autoimmune) which are rarer.

However, not enough research has been done to tell us specifically all the causes and this is the reason that it is called idiopathic (which means no known cause).

Could appendicitis/surgery for this cause gastroparesis? My gastroparesis and Pots started shortly afterwards.

In people with the hypermobile variant of gastroparesis, there is usually an environmental trigger that sets the condition off in genetically susceptible individuals. The trigger may be Covid-19, a vaccine, gastroenteritis, viral infection, or surgery.

With prokinetics, how often should I cycle between different medications?

To avoid becoming desensitised to their effects, people with gastroparesis may benefit from monthly cycling their tolerated prokinetic medicines. This should be discussed with a gastroenterologist for further advice.

Have you seen many cases with people with neurological disorders?

Gastroparesis can occur in people diagnosed with Parkinson’s disease, multiple sclerosis and other neurological disorders. It might be related to the neurological condition itself, or to the side effects of the types of drugs used to treat these neurological conditions. Damage to the vagus nerve because of a neurological condition will certainly cause gastroparesis. Do not stop taking any prescribed medication without discussing it with your GP, consultant or pharmacist first. They may be able to advise alternatives if you suspect a medication side effect.

What is the relationship between gastroparesis and MCAS (mast cell activation syndrome)?

The common factor for both is Ehlers Danlos Syndrome (EDS). From clinical experience, there is a clear association between MCAS and Ehlers Danlos Syndrome (EDS). Once the genetics of both conditions is understood, the answer will become more evident, but more research is needed.

Is there a link between hypothyroidism and gastroparesis?

There is a link between gastroparesis and some autoimmune disorders, including Hashimoto's thyroiditis, leading to underactive thyroid (hypothyroidism). If you also have altered bowel symptoms then your GP can request a test for coeliac disease, as there is also a link between underactive thyroid and this condition.

With hypermobile/MCAS, do you find that it can be progressive?

The hallmark of motility disorders of the gut is the variability of symptoms. People often report exacerbations (flares) and periods of remission that are completely unpredictable. The natural course of the condition is also variable: some patients can have symptoms for a few weeks which improve, then recur a few months later; others have a slowly progressive course.

Is taking prucalopride a long-term solution or is there a chance the effects will wear off and another treatment option will then be required?

Long-term prucalopride use can result in the medicine not working as well (a phenomenon called tachyphylaxis). If it helped before, then it is worth stopping it for at least four weeks before starting it again to see if it works another time. This advice needs to be discussed with a pharmacist or your doctor before changing your medicine.

Is vagus nerve damage reversible?

If symptoms appear immediately after vagal injury, they may be transient (lasting only for a short time). If symptoms appear months or years after the injury, then they tend to be permanent.

Can gastric pacemakers be given to people with a low BMI, or do they need to be in a healthy weight range?

The success of gastric pacemakers relies on patient selection. If suitable, people will greatly benefit from gastric pacemakers, and it may be the only way to improve their low BMI in the long-term. On the other hand, your doctor needs to make sure the person being put forward for surgery is fit enough. Sometimes fitness can be improved by a period of NASOJEJUNAL feeding before surgery. There is a treatment pathway being developed for healthcare professionals.

Can eating disorders like anorexia cause gastroparesis?

From clinical experience, people with gastroparesis, particularly those who also have EDS, often report a period of anorexia in their teens. Even after they recover from their eating disorder, patients with gastroparesis can be misdiagnosed with anorexia, when in fact they have acquired delayed gastric emptying. It is hoped that more research into this area in the future will help us to better understand the link between eating disorders in young people and gastroparesis.

Why do some people gain weight? People say it isn't genuine.

It is a common misconception that if someone is overweight, they cannot have gastroparesis. Some patients gain weight when they develop gastroparesis, while others lose weight. When gastroparesis is treated, people who have lost weight can regain weight and return to their normal weight, whilst those who have gained weight can lose it.

Do you believe MALS is under investigated as an explanation for gastroparesis?

There are two structural conditions which need to be excluded which mimic gastroparesis: MALS and SMA syndrome. Both can be excluded with an MRI or CT scan. However, very thin patients can have what is known as pseudo-SMA syndrome because the fat pad between the aorta and the SMA is lost.

Further information

If you asked a question that hasn't been answered, it's likely that the question you asked is individual to you and your experiences. We recommend speaking to your GP or consultant for information about any specific questions you might have relating to your condition or symptoms.

Guts UK's expert information about gastroparesis symptoms, diagnosis and treatment can be found at www.gutscharity.org.uk/advice-and-information/conditions/gastroparesis/.