

Spring/Summer 2023

**GUTS
UK!**



With families like Kirsteen's by our side,

we take one giant leap closer to finally getting to grips with guts!

Kirsteen supported Guts UK for the first time after her dad, Brian, passed away from pancreatitis. Her family found themselves turning to our information yet again after Kirsteen's brother, Paul, was diagnosed with bowel cancer.

Kirsteen has taken on the huge challenge of running the London Marathon for Guts UK this year.

Days before Paul died, Kirsteen was wearing her guts gear, ready for a run. Paul told her "you look the nuts". Kirsteen has worn her 'You Look The Nuts' t-shirt whilst training ever since.

"I'm taking this on with plenty of trepidation, but bucket loads of determination. Running has been my anchor through the stormy seas of the last three years. Our family have raised over £10,000 for Guts UK. This is another way for us to support this small but mighty charity, who now feel like part of our extended family. Every step of this run is for my beloved dad and brother".

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A lasting legacy

A lifetime of change

A gift in your Will to Guts UK is a gift of hope.

"You cannot take anything with you when your time is up here on earth. When making a Will, you decide what kind of legacy you'd like to leave behind. Digestive conditions are part of my everyday life. I want to support Guts UK's important work, even whilst I'm gone" - Guts UK Supporter.

Our guts have been underfunded, misunderstood and neglected for decades. When you support Guts UK with a gift in your Will, you help us get to grips with guts and save lives, for generations to come.

Contact us today for more information.

Don't be a stranger!



We **love** hearing from you; it's the best part of our job.



@GutsCharityUK



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It's time to get

the nation talking about their guts

Guts. We all have them. Around 25ft of them. Every now and then, they rumble and when they are full, we give them a pat. But as a nation, we don't like talking about our guts.

Our research found that **58% of people are embarrassed to talk about their digestive condition or symptoms.**

We know that there's a crippling taboo surrounding our digestive system. But if we don't talk about our symptoms, how do we know where to turn for help?

Frighteningly **51% of people delay seeking help for their digestive symptoms for 6 months or longer.**

This can lead to people suffering in silence. Feeling like you're the only person in the world struggling is a lonely place to be. Guts UK exists to change that.

“ The responses to my requests for help and advice from this organisation have been sanity-saving. ”

“ Guts UK are so generous with their knowledge and time. I am now more at ease and empowered to take the appropriate actions to better my health. ”

“ I've been on a diagnosis journey for just over 10 years now. If it wasn't for your charity and your information, I wouldn't have known to push further on tests for specific conditions. [My diagnosis and treatment] has made a massive difference so far, and it's thanks to you! ”

Your support empowers people to seek help sooner, change lives and finally help the UK get to grips with guts!

Please donate today.



Is it definitely Irritable Bowel Syndrome with Diarrhoea (IBS-D?)

What is IBS-D and how is it diagnosed?

IBS-D is IBS with predominantly diarrhoea symptoms. To reach a diagnosis of IBS-D, your doctor will need to rule out a number of other conditions that also cause diarrhoea.



What conditions should my doctor test me for first?

Coeliac disease:

This is an autoimmune condition occurring in those who become sensitive to a protein called gluten in their diet. **To diagnose coeliac disease, you need to continue eating gluten whilst under investigation.** Your doctor may organise a blood test or an endoscopy (a camera into your small bowel). Symptoms include:

- In children:**
- Diarrhoea, vomiting or failure to gain weight
- In adults:**
- Bloating, abdominal discomfort, abdominal pain, diarrhoea, constipation or unexplained weight loss
 - Skin rashes
 - Loss of sensation to fingers and toes
 - Coeliac disease can sometimes be suspected if tests show anaemia, or weakened bones (osteoporosis)

Bowel cancer:

To be on the safe side, **your doctor may send you for investigations to rule out bowel cancer.** This could include a camera looking at the bowel (a colonoscopy or sigmoidoscopy). Symptoms include:

- Change in bowel habit (such as unusual episodes of diarrhoea or constipation)
- Abdominal pain or weight loss
- Bleeding from the bowel/blood in the poo

Crohn's disease:

This is a condition in which **inflammation develops in various parts of the gut.** It is part of the Inflammatory Bowel Disease (IBD) group. Your doctor may request a blood sample and a poo sample (known as a faecal calprotectin test). Symptoms include:

- Diarrhoea and abdominal pain
- Blood or mucus in the poo, especially if the lower bowel is affected
- Unintentional weight loss
- Extreme tiredness, low mood or poor sleep

Ulcerative colitis:

This is also part of the IBD group, **an inflammation of the rectum and large bowel.** Your doctor may request a blood sample and a poo sample (known as a faecal calprotectin test). Symptoms include:

- Diarrhoea and abdominal pain
- Bleeding from the back passage
- Extreme tiredness



After your doctor has ruled out the previous conditions, you may be given a formal diagnosis of Irritable Bowel Syndrome. There are other digestive conditions that can cause diarrhoea too. Your doctor may not immediately organise any tests regarding these conditions, but it's worth being aware of them.

Bile Acid Malabsorption / Bile Acid Diarrhoea (BAM/BAD):

This condition is where bile acids are not properly re-absorbed from the end of the small bowel, and pass through into the large bowel. **This can only be diagnosed by a test called the SeHCAT scan.** The diarrhoea is usually:

- Frequent, during the day and sometimes at night
- Pale, greasy and hard to flush away. It may also be unusually coloured (green, orange or yellow)



Pancreatic Exocrine Insufficiency (PEI):

This can be caused by any disease that affects the pancreatic tissue. The most common causes are cystic fibrosis, acute and chronic pancreatitis, and pancreatic cancer. But you can have PEI without the above. If PEI is suspected, diagnostic tests will look at the structure of the pancreas (such as an ultrasound, CT or MRI scan). Tests will also see how well the pancreas is working, using a poo test (faecal elastase-1). Symptoms include:

- Abdominal discomfort, pain, bloating or wind
- Fatty poo (steatorrhoea) that can look bulky, oily, pale orange or yellow, foul-smelling and runny
- Poo can be difficult to flush and may stain the toilet bowl
- Weight loss

Microscopic colitis:

Though microscopic colitis is also an IBD (like Crohn's disease and ulcerative colitis), **it is diagnosed differently as it cannot be seen during colonoscopy.** To diagnose microscopic colitis, biopsies (small samples of tissue) must be taken during a colonoscopy, and examined under a microscope. Symptoms include:

- Watery diarrhoea
- Incontinence episodes and urgent, frequent need to use the toilet
- Waking during the night to empty the bowel



Guts UK has expert information on all of the above conditions, including IBS. Please contact us. We're here to help, so that no one suffers in silence or alone with their symptoms.

**Did you find this information useful?
Help us help the next person, by donating today. Thank you.**

Our wonderful community covered hundreds of miles in 2022 for Guts UK.

You can take us one step closer to getting to grips with guts in 2023!



Kristina ran the London Marathon in 2022 in memory of her Aunt and her Grandma. Both passed away from oesophageal cancer.

Mark ran the London Marathon for Guts UK. His wife and son cheered him on the whole way!



Rhys ran the London Marathon for Guts UK in memory of his mum's partner, Rob, who they lost to oesophageal cancer.



Christian ran the London Marathon in memory of his father-in-law, Graham. Alongside his wife, Milly, they raised £25,000 for Guts UK last year!

Jon and Terry met at the London Marathon after both running for Guts UK. Jon has coeliac disease, and Terry ran to support his friend, Abi, who has achalasia.



Together our London Marathon and Big Half runners raised £16,756 for Guts UK in 2022! We are beyond grateful to each and every one of them.

Be part of something wonderful!

Guts UK has places in this year's Big Half Marathon on Sunday 3rd September 2023 in London.

"Myself (Donna) and my brother Paul did The Big Half Marathon in memory of our dad, Barrie. Pancreatitis took Dad from us so suddenly. We felt completely helpless and wanted to take back control.

I felt so nervous in the lead up to the half marathon. I'd never done anything quite like this before! I remember crossing the line on the day, exhausted and emotional. I'd done it. We'd done it. The feeling as you crossed the finish line was amazing. I'd encourage anyone to sign up. The atmosphere on the day was so fantastic!"

People are suffering and people are dying, all because of a lack of knowledge about our guts. Run The Big Half Marathon for Guts UK, and together, we will get to grips with guts faster.

To secure your place, contact us today!



Diverticular disease: back to basics

When it comes to diverticular disease, there are a lot of similar sounding words. It can be confusing (and quite the mouthful)!

- **Diverticulosis:** this is the presence of pouches in the bowel wall.
- **Diverticular disease:** this is diagnosed when these pouches give you symptoms.
- **Diverticulitis:** this is when one or more of the pouches become inflamed or infected.

Who does it affect?

Diverticular disease is very common in the developed world. In fact, between 1 in 3, increasing to 1 in 2 people will be affected during their lifetime. Though researchers are still unsure what causes the pouches to develop, after the age of 40, they become more common.

What are the symptoms?

The most common symptoms include:

- Lower abdominal pain (often crampy)
- Change in bowel habits (diarrhoea or constipation)
- Bloating
- Mucus or blood in the stool

In most people, the pain is focussed on the left side of the abdomen, where these pouches most often occur. But in a small number of people, and those of South Asian origin, symptoms may occur on the right-hand side.

If you experience a change in symptoms or develop new symptoms, especially blood in your stools, consult your doctor.

Symptoms to be aware of:

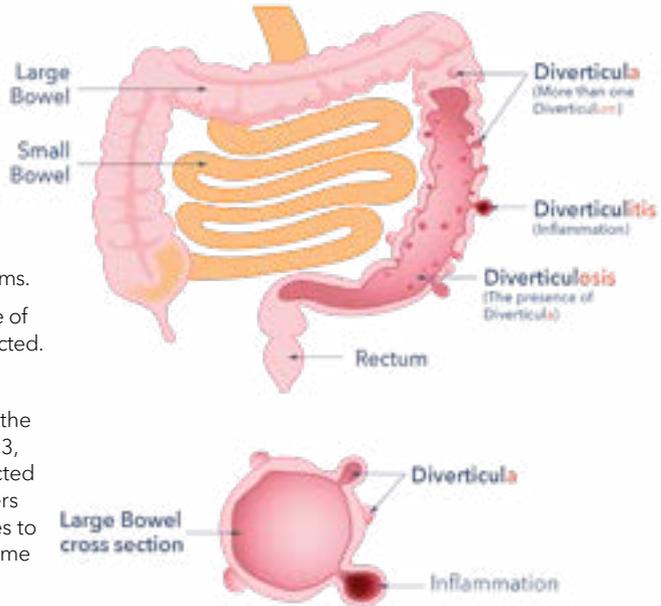
Diverticulitis is an infection or inflammation of these pouches. This can happen in between 1 in 10 to a quarter of people. If any of the below symptoms are experienced, medical help should be sought immediately:

- Worsening abdominal pain
- High temperature
- Nausea (feeling sick) or vomiting (being sick)

The myths - diet!

If you look on the internet, you will likely come across older information about diverticular disease, and wrong advice about certain foods. You may have read or heard that those with diverticular disease should avoid tough fibre, such as seeds, nuts, popcorn and fruit skins. The latest evidence shows that you don't need to avoid these foods. They can be consumed as part of a healthy, balanced diet.

There are no foods you need to avoid, or eat in particular when you have diverticular disease. You are advised to eat a healthy, balanced diet including fruit, vegetables and wholegrains.



We believe that evidence-based information is powerful. With you by our side, we can reach those struggling in silence and alone. Donate to Guts UK today.

Nanette's Story

Pancreatitis



Tell us a little bit about you

I'm Nanette, I'm 73 years old, married with two children and two grandchildren. My husband, Steve, and I are retired and live in Scotland. We met at a parachute club - I joined thinking I'd meet a rich Scotsman, but ended up with a poor Yorkshireman!

Can you remember when your symptoms began?

I'd just returned home from volunteering in the community. I had a sudden, sharp pain in my upper abdomen. I thought it was indigestion, but it worsened very quickly. I have never in my life experienced such a pain. I knew it was serious, and called out to Steve to call 999.

By now, I was on my hands and knees. My abdomen was swelling in front of my eyes, becoming hard. I could hear a dreadful groaning, like an animal. I realised it was me.

Can you remember your time in hospital?

I can remember being taken off in an ambulance. Steve had tried to come with me, but COVID restrictions were still in place. Steve was upset, and I remember watching him stood helplessly on the drive. **I really believed that would be the last time I'd ever see him.**

My time in hospital is mostly a blur. I had severe acute necrotising pancreatitis. I spent four weeks in intensive care. Doctors met with Steve to prepare him for the possibility of me dying.

When were you moved out of intensive care?

I'd moved out of intensive care for my last two weeks in hospital, and I can remember them a little better. It hit us all just how close to death I was.

I was finally allowed home, but the recovery was a long process. I was told it would take me around a year to recover, which I didn't believe. But it did.

*Nanette, Steve
& Katy*

I was grateful that Katy, our daughter, had found Guts UK online. It helped us understand what happened to me. I felt I'd been left by my doctors and the hospital to just 'get on with it'.

How are you now?

I'm so grateful to feel well again. It was a long journey. I had many complications along the way, like sepsis and a pseudocyst. I no longer have my gallbladder, as consultants thought my pancreatitis was caused by gallstones. My life has changed - I have Type 3c diabetes and I still take prescription pancreatic enzymes to help me digest my food correctly, but I am so grateful to be given a second chance. I feel so fortunate.

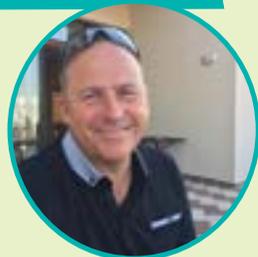
Guts UK's awareness raising and story sharing moves me to tears. I want to show people that there is hope. I appreciate all Guts UK do, knowing they're there means everything.

You make it possible, Nathalie and family:

When Nathalie's husband, Peter, passed away due to pancreatitis, their family chose to support Guts UK at his funeral. Loved ones also ran the Bournemouth 10km in his memory last year. They have raised over £6,000 in Pete's name.

“None of us had enough time with Pete. We hope that by raising money to fund research, information and awareness into this devastating disease, we can spare families of the future the enormous pain we are bearing.”

Thank you for choosing to remember Pete by helping others.



Your Top 10 Research Priorities

for pancreatitis are here!

In 2021, we began identifying the Top 10 Research Priorities for pancreatitis in the UK. Over 1,700 questions were submitted from patients, families and healthcare professionals. Now, we're filled with pride to announce your top 10 priorities for acute and chronic pancreatitis research, in both children and adults.

- 1 Are there better ways to treat and manage acute and long-term pancreatitis pain, for example using non-opioid (painkillers) drugs?



"Oli depended on opiate-based painkillers, as others wouldn't touch his pain. He became dependent on them. Opioids take the pain away, but they alienate the person. They can create a bigger struggle for the person than the illness that they are meant to be treating" - Oli's family

- 2 What can be done to prevent pancreatitis becoming worse, and to stop or reverse the damage to the pancreas?
- 3 Are there better ways to reduce inflammation in people with pancreatitis, both in the pancreas and the rest of the body?
- 4 How can pancreatitis be diagnosed more quickly and accurately, especially on admission to hospital?

"From two years old, Jemma and James (our children) were in and out of hospital with abdominal pain. James was accused of being an attention seeker, and Jemma had her appendix removed. James had to wait 12 years for his diagnosis, and Jemma waited 21 years. Early diagnosis is essential, improving physical and mental health, and avoiding unnecessary pain and surgery" - Katie, Paul and the Ward family



- 5 How can people with pancreatitis be helped to manage their condition post-diagnosis (after being diagnosed) e.g. by giving information about diet, medication and lifestyle changes?



"I left hospital with no information or advice. I had no knowledge of what happened to my body during my five months in hospital. I want to see more support, advice and information so people don't feel 'turfed' out of hospital, struggling alone. I want to see people with the information that I never had" - Mandy

- 6 Are there better ways to treat and manage flare-ups (when symptoms get worse) in people with chronic pancreatitis?
- 7 Can gene therapy (altering genes inside the body's cells) be used to treat people with pancreatitis?
- 8 How can multiple organ failure be prevented in those people with pancreatitis who become seriously ill? How can the care of those with multiple organ failure be improved?
- 9 How can pancreatic cancer be diagnosed earlier in people with pancreatitis?
- 10 What are the psychological (mental and emotional) impacts of pancreatitis? What are the best ways to treat and support people (both young people and adults) with pancreatitis who experience mental health problems?

What's next?

A focus for pancreatitis research in the UK has been decided. The National Institute for Health and Research (NIHR) welcome applications for research towards conditions with top 10 priorities.

Read more: gutscharity.org.uk/Pancreatitis-Top-10

Pancreatitis has been misunderstood for too long. Your donations change that. Please donate today.

Thank you for helping

get to work with

Every bake sale, run, or walk to be there for those who need it. Every walk, sky-dive or step closer to getting it. Whatever you decide.

Our fundraisers inspire you. feeling inspired too? Help us with guts by funding your challenge today. 0207 486 0341 • info@gutsuk.org



Martin's miles:

Martin started his new year off with a bang! He cycled 660km throughout January for Guts UK. Martin has Familial Adenomatous Polyposis (FAP) and Gardner Syndrome.

We cannot thank Martin enough for his support and dedication to our small but mighty charity.

← *Martin*

Hannah's February fitness:

Hannah →

Hannah is an upper GI nurse. For oesophageal cancer month in February, she wanted to go the extra mile. She challenged herself to complete 28 sit ups and run one mile per day for the whole month. It warmed her heart (and ours) when her patients wanted to support her challenge too.

She raised £235 for Guts UK!



Megan & her siblings →

Megan's family

In 2021, Megan passed away from pancreatitis. For Megan's 13th birthday in 2022 her mum, Jess, wanted to do something special to remember her little girl. They held raffles and threw a disco. Megan's family and friends raised over £1,000 in her memory and they aren't stopping there.

Megan's grandma, Karen, is supporting her partner Mark as he takes on the Fred Whitton challenge (cycling 183 km) this year.



← *Megan & her mum, Jess*



you for
the UK

grips
guts!

head shave enables us
with digestive diseases.
or climb takes us one
grips with guts.
le to do, thank you.

us every day. Are you
help the UK get to grips
fundraising today:
@gutscharity.org.uk



Nicole's family

Nicole had gastroparesis. She passed away at 29 years old, and her loved ones have supported Guts UK in her memory. Her friend Jordan climbed Ben Nevis and now her mum is organising a ladies' day in her memory.

This was a yearly family tradition that Nicole loved.

Nicole



Amy & Ben's wedding bells:

Amy and Ben chose to share their big day with Guts UK. Amy was diagnosed with Crohn's disease at a young age.

On their special day, they raised a wonderful £310 to help others just like Amy.

Amy & Ben

Joe is jumping from the skies:

Joe is jumping out of a plane for Guts UK in memory of his mum, Lisa. Lisa passed away from oesophageal and liver cancer. His family have already raised over £2,000 in her memory and Joe is determined to celebrate her life and everything she meant to him again this May. **We are so grateful to all of Lisa's loved ones for their continued support in her memory.**

Joe



Rachael's Story

Oesophageal cancer



Tell us a little about yourself

I'm Rachael, I'm 43 years old living in Manchester. I'm a creative person with a design background, and an active member of my Church.

Can you remember when your symptoms began?

Around three years ago, I was a workaholic. I swung precariously high on the career ladder, until the upper rungs didn't bear my weight so well anymore and I fell. I experienced burnout. I was physically and emotionally exhausted, and left the business for my wellbeing.

In 2021, **I was ready to work again but out of nowhere started experiencing acid reflux.** The simplest of foods, like porridge or mashed potatoes would be an issue to digest. Within weeks I couldn't even swallow water.

When were you diagnosed with oesophageal cancer?

On my third walk-in to A&E they admitted me in as a patient, gave me fluids and a feeding tube. A week later, I was told I had a rare, advanced form of oesophageal cancer.

How did you feel?

I wasn't angry or scared. I was just confused. **It didn't make sense to me, given my age and lifestyle. But thankfully, my cancer hadn't spread** and I had a wonderful support network in place.

I had chemotherapy, followed by an oesophagectomy (surgically removing some or most of the oesophagus), then further chemotherapy. The chemotherapy gave me an awful lot of nausea, vomiting and dry retching.

What did you find most difficult?

My oesophagectomy affected me more than I could've known. Food was a big part of my life. The old version of me would gallivant through Manchester, discovering new places to eat and socialise. Switching to a liquid diet was incredibly hard. The food and textures that I crave the most can now become stuck in my oesophagus.

How did you get through this period?

I wanted to talk about where God fit into this mess. I'd speak with Christians who had a long history with the Lord and had experienced difficult periods themselves. This was a form of talking therapy to me. **I could process my anger, confusion and ultimately my grief.** I healed during this process, gaining so much wisdom.

How are you now?

I'm currently in remission from cancer, settling into my new normal. As a recovering workaholic, embracing simplicity was an inevitability for me.

If anything, **oesophageal cancer has taught me life is fleeting and shorter than we anticipate.**

I don't want to wait around for my purpose and passions to unfold passively. I must seize what's in front of me and encourage others to grow and run on the journey with me. That's the definition of good leadership. This is part of the reason I'm sharing my story today.

You make earlier diagnosis of oesophageal cancer possible, Nicola:

“ When Paul passed away, Nicola (Paul's partner) and Harrison (Paul's son) supported Guts UK at Paul's funeral. They raised over £365 in his memory, for other families. Their support helps fund research aiming to understand oesophageal cancer better, and diagnose oesophageal cancer sooner, giving people a fighting chance. Thank you. ”



Paul & Harrison

Our Experts By Experience (EBEs)

Our EBE panel are a fantastic addition to our small but mighty team. This panel is made up of those living with a digestive condition. They ensure that those with digestive diseases are at the heart of all we do and the decisions we make.

We're proud to say that this panel assists in deciding which research Guts UK funds, alongside UK medical experts.

“ I have an interest in patient involvement and engagement within research from the planning stages through to dissemination. I am particularly interested in how research projects can be made more accessible to the disabled community. ”

- *Michael (he/him), EBE member, gastroparesis and acid reflux.*



“ Having suffered with gut problems for many years, I know what an impact it can have on your life. It took a long time for me to get a diagnosis and there's still so much we don't understand about our guts, which better research can help us unlock. ”

Having a gut condition can make you feel alone as it's not the easiest thing to talk about, so making sure the voices of patients are heard throughout research is something I'm really passionate about and why I love being part of the Guts UK EBE team. ”

- *Grace, EBE member, coeliac disease and Bile Acid Malabsorption.*



We wanted to say a huge thank you to each of our EBEs for ensuring the patient voice, your voice, is heard in every decision we make.

- **Harinder**, representing ulcerative colitis
- **Dave**, representing oesophageal cancer
- **Lucy**, representing achalasia
- **John**, representing pancreatitis
- **Liz**, representing pancreatitis
- **David**, representing congenital bowel disease
- **Sofie**, representing Irritable Bowel Syndrome (IBS)
- **David**, representing pancreatitis
- **Beverly**, representing biliary sphincter disorders

Rahul's

Irritable Bowel Syndrome (IBS)

Story



Tell us a little bit about you!

My name is Rahul (he/they). I am a queer, trans, disabled, neurodivergent brown person. I am an artist, musician, web designer and generally creative. I'm an ambassador for the organisation Chronically Brown, which is a not-for-profit company for the disabled South Asian community.

Can you remember when your symptoms began?

I remember sitting in class in school, **desperately trying to hide and ignore my stomach cramps and pain**. At the time, I had other undiagnosed chronic illnesses. My 'gut' symptoms were not my most severe symptoms, so I didn't address them for a long time.

When were you diagnosed with IBS?

There were months where I was having such bad gastric pain every time I ate, that I struggled to eat anything. I finally thought I should get help, and saw a gastroenterologist. After a few tests to rule out other conditions, I was diagnosed with IBS.

As a child, I didn't realise that most people are not in physical pain every day, because I just assumed my experience was normal. **I really thought that digestion was inherently painful.**

What are your usual symptoms?

My IBS symptoms include stomach cramps, bloating, constipation, diarrhoea, and nausea. But due to my other chronic illnesses, it's not always easy to separate which symptoms are caused by which illness.

How does this affect your day-to-day?

More recently, my symptoms are less severe. I still

experience symptoms every day, but I am grateful that it is milder now.

I struggle with being self-conscious when my symptoms are worse, like **when I have such bad bloating that I almost look pregnant, or when I accidentally fart in public and it smells really bad**. I have previously blamed my dog for a few of the stinky farts (sorry Moya!) There is a lot of stigma around discussing gut health, and many people believe it is too gross to talk about.

What do you find helpful on a difficult day?

Dietary changes work well for me, but it is very hard to figure out what changes to make. There is lots of misinformation and conflicting information about diet and what is "good" for you and what is "bad". Diet culture makes us believe that there is a distinct line between healthy and unhealthy foods, and we need to realise that there is no universal "good" or "bad" foods. All foods have their benefits, and all foods can cause problems in excessive quantities. Everyone is different. I think the only way you can really figure it out is by trying different things out.

What are your hopes for the future?

I hope our society can discuss gut health more openly. **Hearing other people talk about their chronic illnesses helped me so much when I was struggling to understand and accept my own illnesses.** By sharing my experiences, I hope to help someone else in the same way.

Your Top 10 Research Priorities

for Irritable Bowel Syndrome (IBS) are here!

In 2021, we began identifying the Top 10 Research Priorities for IBS the UK. Over 8,000 questions were submitted by patients, families and healthcare professionals. Now, we're overjoyed to announce your top 10 priorities for UK IBS research in adults.

- 1 Are all forms of IBS the same condition, or are there different types of IBS with different causes, needing different treatments?

"As clinicians, we've learnt that a 'one size fits all' approach to treatment of IBS is inefficient. Personalising care is a top priority. It will allow professionals to recommend the right treatment, at the right time, for the right patient" - Dr Dipesh Vasant, Consultant Gastroenterologist.



- 2 What causes bowel urgency (a sudden, urgent need to go to the toilet) in people with IBS? How is this best treated and managed?

"Sudden urgency is the feeling that stops us from living a full life, giving sufferers the biggest anxiety. This question is important as it has such a significant impact on sufferers with IBS" - James



- 3 What causes pain and/or gut hypersensitivity in people with IBS, including spasms and cramps? Are there better ways to treat and manage these?
- 4 Could a better understanding of the gut-brain connection in IBS lead to the development of new treatments?

"I have experienced a lot of anxiety with IBS which has a huge impact on my gut. The days where my anxiety is high are the days that my IBS is at its worst. While healthcare professionals know about the gut-brain connection in IBS, I believe further research could find a whole host of new ways to approach this, and hopefully develop new treatments" - Tiegan



- 5 Do hormonal changes during the menstrual cycle, pregnancy and menopause affect IBS symptoms? If yes, could this understanding lead to new treatments?
- 6 How does mental health, particularly anxiety and depression, affect IBS? Do treatments for anxiety/depression reduce or stop IBS symptoms?
- 7 Are there ways for people with IBS to improve sensitivity in the bowel and/or improve control of their bowels e.g. through training with biofeedback?
- 8 How can a fast and accurate diagnostic test be developed for IBS? How can different types of IBS be diagnosed more reliably?

"A fast diagnostic test would help people begin the process of understand and treating their IBS sooner. It also tracks how many people live with IBS" - Morgan



- 9 What changes in diet benefit people with IBS? Which diet is best for the long-term?
- 10 Are treatments which balance the gut bacteria effective for people with IBS, including faecal transplants? Which prebiotics and probiotics are most effective?

"There's a bewildering amount of information on the web about the microbiome and prebiotics/probiotics. My wife has fought IBS for nearly 40 years, trying many remedies. We need to better understand the microbiome and its relationship to IBS" - Peter



What's next?

The future looks brighter. A direction for IBS research in the UK has been decided. The National Institute for Health and Research (NIHR) welcome applications for research towards conditions with top 10 priorities.

Read more: gutscharity.org.uk/IBS-Top-10

IBS has been neglected for too long. We're changing that. Your donations make life-changing research possible. Support Guts UK today. Thank you.

Gastritis

What is gastritis?

Gastritis is where the lining of the stomach becomes inflamed. It can be acute (recent onset) or chronic (long-term). It is not the same as gastroenteritis (inflammation in the bowels).

Gastritis is common. It's reported that more than half of the world's population has chronic gastritis. Normally the mucus lining the stomach protects it from digestive juices such as stomach acid and bile. Gastritis occurs when this protection is weakened, and digestive juices cause inflammation.

What are the symptoms of gastritis?

Symptoms can vary from one person to the next. Some may not experience any symptoms, but common ones include:

- Indigestion
- Feeling sick and being sick
- Feeling full after eating
- Stomach pain (often described as 'burning' or 'gnawing')
- Very rarely, severe gastritis can cause bleeding which may turn the stool black (melena)

If indigestion lasts longer than three weeks and your symptoms are severe, you have blood in your poo or vomit, or changing lifestyle factors have not been effective, see your GP.



What are the causes of gastritis?

Common causes of gastritis include:

- Bacterial infections such as helicobacter pylori and herpes simplex
- Medications
- Lifestyle factors - such as excessive alcohol intake, recreational drug use and smoking cigarettes

How is gastritis diagnosed?

- If your GP suspects you might have a helicobacter pylori infection, they may ask you to undergo a breath or poo test.
- Another way to diagnose gastritis could be during an endoscopy (a camera looking at the stomach). Small samples of your stomach lining may be taken to later be examined under a microscope.
- For those unable to have an endoscopy, you may be asked to do a barium swallow and x-ray. The barium coats the surface of the stomach and can highlight abnormalities.

What treatment is available?

Your doctor may suggest lifestyle changes such as stopping smoking, recreational drug use or reducing alcohol intake. Medicines may be advised, depending on the cause of the gastritis and your symptoms such as:

- Antacids - reduces the amount of acid produced by the stomach.
- Alginates or sucralfate - form a protective layer or layer on top of the stomach or on the stomach lining.
- Acid-suppressing medications such as PPIs or H2 blockers, that reduce the amount of stomach acid produced.
- Antibiotics may be used if your gastritis was caused by a bacterial infection.

What are the complications of gastritis?

Those diagnosed with autoimmune atrophic gastritis or with a long-term helicobacter pylori infection may have a small risk of developing stomach cancer, though most people will not.

If you experience symptoms such as being sick, difficulty swallowing, weight loss, pain, blood in poo, reflux or dyspepsia, contact your GP.

Guts UK's research:

We're proud to fund Dr Marnix Jansen's stomach cancer research. Dr Jansen's team are exploring the current methods that are used to take tissue samples from the stomach, evaluating if these can be more effective. They are also exploring the DNA changes that occur during stomach cancer. This research has the capacity to save lives. Your support can turn scientists' determination into life-changing discovery. Support Guts UK today.



For more detailed information with the full list of treatments and causes, go to:
gutscharity.org.uk/gastritis

James' Story

Achalasia

Tell us a little about yourself:

I'm James, I'm married to Julie-Ann with a daughter, Jaz. Before achalasia, I did karate and even managed to become an intermediate dan grade! Now, I'm a keen cyclist.



James with his daughter Jaz

When did you first notice symptoms?

My wife and I got a takeaway one night. She noticed me struggling to finish my food, and I'm normally the first person to finish, but I felt sick. If I'm honest, I didn't take much notice that I couldn't finish meals at first. But then a strange chest pain started.

I had a phone consultation with a doctor in 2021. NHS services were delayed, and no one saw me face to face to see what was wrong or how much weight I'd lost. My mum rang the surgery pleading with them saying 'he's wasting away in front of us'.



How long did it take for you to be diagnosed?

It took 5 months of referrals until I got my achalasia diagnosis. Those 5 months were hard. I was hungry, tired, and fed up. I even had to take time off work. The only thing I didn't struggle to eat was jelly babies.

I felt relieved when I finally received my diagnosis. They'd finally figured it out and something was going to be done about it. I ended up having the heller's myotomy operation (this procedure aims to permanently improve swallowing).

I was also referred to a dietitian. It's safe to say they weren't happy with my jelly baby diet! I was booked for a feeding tube.

How is your day-to-day life living with achalasia?

When I was first in hospital, I had hope for the future. I wasn't prepared for what was yet to come.

When I was in recovery, it was hard for my daughter Jaz to see me like that. We'd say, "Daddy's not well, he's got a bad tummy."

When we'd go to the park Jaz would proudly tell other families, "This is my Daddy and he's not very well; he's got a bad tummy." People would stare and have questions. I don't mind. I'd rather people know about achalasia.

Now I don't think people would know I'd been so unwell as I'm doing much better. I can struggle with foods like bread, but I avoid them and eat slowly.



You make it possible, James:

“Though I might struggle with swallowing food, what I can do, is ride a bike! In September I cycled 100 miles and raised over £1,500 for Guts UK. I needed to do something to help others.

I took part in the #GUTSelfie online campaign too, where hundreds of people came together to share their experience of digestive diseases to raise awareness. It meant a lot to me to find other people going through something similar. People deal with things in different ways, but to be able to talk about it to someone who's been through it, is better than being alone.”



How you're raising the banner for digestive health!

This is Ariya. She proudly told her class how she and her mum, Pie, raise awareness for digestive conditions like ulcerative colitis.



Ariya →

For the last 2 years, they've taken part in Guts UK's social media campaign, #GUTSelfie.

Guts UK and the Less Survivable Cancers Taskforce hosted a parliamentary event in February at Westminster. Guts UK asked Gill to come with us, who lost her husband Tony to stomach cancer in 2019. This was her opportunity to tell Tony's story, and allow his legacy to live on by changing the future for others.



Rachael shared her oesophageal cancer journey with Guts UK. She then joined us on Channel 4 Evening News to talk about why our oesophageal cancer research is so important to people just like her.

Rachael →



Our community have been helping us share our information far and wide! From Northgate Practice in Walsall, to Warrington & Vale Royal College, and University Hospital of Wales. You've been helping us get expert information into the hands of people who need it most.



John's Story

In one day, John went from putting up a new kitchen cupboard to lying in a hospital bed.

John and his daughters, Julie & Susan

When John complained of indigestion, Julie and Susan, John's daughters and her mum Sandra thought little of it. Two hours later, John was grey, soaking with sweat and unable to speak due to the intensity of the pain he was feeling.

John was rushed from his home in Wales to hospital, where his family were told he had acute pancreatitis. "John's condition is worsening, and there is no treatment", the doctors told his family. John's organs were failing, and he was moved to intensive care.

Just seven days after John was putting up a new kitchen cupboard, Sandra, Julie and Susan were called to the hospital to say goodbye to their husband and father.

Too many people like John are suffering and dying, because there are too many unanswered questions about our guts.

John and Sandra →



YOUR STORIES

You can end the pain, suffering and death by supporting Guts UK today

Let's get to grips with our guts, and save lives

www.gutscharity.org.uk

**GUTS
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- Rumination Syndrome
- Stomach Cancer
- The Mediterranean Diet & Gut Health
- The Role of Gut Bacteria in Health & Disease
- Ulcerative Colitis
- Wind, Burping, Flatulence & Bloating

NEW

NEW

NEW



Much more information on conditions, health and lifestyle tips can all be found at gutscharity.org.uk

You can request your free of charge hardcopy in the post by emailing info@gutscharity.org.uk or calling 0207 486 0341.

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Donation Form **I'm getting to grips with guts!**

Please return this form to:

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£5 £10 £25 £50 £100 £500 Other £

We would love to be able to send you the latest research updates, fundraising activities and the latest news on the impact your support is having on our work to end the suffering for the millions affected by digestive diseases. Let us know below how you prefer to be contacted.

<input type="checkbox"/> Yes, I would like to be updated by email	<input type="checkbox"/> Yes, I would like to be updated by phone
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To make any changes to your preferences, email **info@gutscharity.org.uk** or call us on **020 7486 0341**

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