



#GutTalk GUIDE

A guide to talking about gut health issues with healthcare professionals, friends, family and colleagues

Introduction

Despite the fact that over half of us (59%) are currently suffering from a gut health condition or symptom or have done in the past¹, research shows many of us feel embarrassed discussing gut health concerns.

Close to half (48%) of those with digestive health conditions admit to being embarrassed by them² and a similar number (46%) of those who delay seeing a doctor for persistent gut problems, do so out of embarrassment³.

Love Your Gut has been raising awareness of the importance of gut health for over 20 years and is seeking to empower **#GutTalk** about gut health issues, with the aim of lessening the embarrassment and taboo which often surrounds the topic.

This guide aims to help sufferers to get the help and support they need and to advise friends, family and colleagues on how best to offer support.

It's good to talk, and **Love Your Gut** hopes this guide encourages everyone to do just that.

⁴ www.nhs.uk/live-well/eat-well/common-digestive-problems-and-how-to-treat-them/

"People with gut health issues often report feeling depressed and self-conscious about their symptoms, which can really affect their quality of life. But by talking about issues with your digestive health, you can help others to understand that you are feeling unwell. There is no need to be embarrassed, in fact 40% of people will be suffering from at least one digestive symptom at any one time⁴, so you are not alone!"

Jo Travers, Dietitian



"It's never easy to talk about something that is a taboo or has a stigma attached to it and the digestive system has been that way for generations. But being diagnosed with a digestive condition made me wake up and realise that health is too important to be embarrassed about. Your gut is a wonderful and complicated organ, strongly connected to our emotions and environment. It's time to get talking and break down the taboo surrounding poo."

Louise Hunt, blogger at Young Crohn's with Crohn's disease



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¹ Research carried out by Mortar London which conducted an online survey among 1,050 respondents across the UK and the Republic of Ireland (1,000 UK/50 ROI) between 16th and 19th July 2017. The sample of adults was randomly selected and weighted to be representative of the populations for age, gender and region.

 $^{^{\}rm 2}$ Guts UK (formerly Core): findings from research with patients, caregivers, and stakeholders, April 2017

³ Research carried out by Mortar London, which conducted an online survey among 2,079 respondents across the UK and Republic of Ireland (1829 UK/250 ROI) between 7th and 10th August 2018

#GutTalk ... With your GP

Although GPs discuss gut health issues with their patients day in and day out, many of us are embarrassed to share details of our symptoms with a doctor. Indeed, close to half (46%) of people who delay seeing a doctor for persistent gut problems, do so out of embarrassment⁵.

For over three quarters of people (83%)⁶, the GP is the first healthcare service people visit about gut health issues, so it's important to get conversations off to a good start. Discussing issues with your GP promptly, openly and clearly is important as it will give you the best chance of getting the right help and support.

Opposite, **Dr Kevin Barrett**, **GP and Chair of the Primary Care Society for Gastroenterology**, shares his tips on talking for before, during and after a GP appointment.

 $^{\rm 6}$ Guts UK (formerly Core): findings from research with patients, caregivers, and stakeholders, April 2017

"GPs are used to dealing with gut health problems and patients should not be afraid to tell them about any symptoms. GPs have almost certainly heard any story before and are virtually un-shockable! Healthcare professionals are used to hearing words such as poo, tummy, bottom and bum, as well as many other words, so you need not be shy about using phrases that you are comfortable with. A GP has many roles and one

of them is to translate the medical jargon that is sometimes still used in hospitals into words that are more meaningful to patients. GPs are human too and gut health problems affect almost all of us at some point in our lives, whether with an episode of gastroenteritis, abdominal cramps and bloating caused by certain foods, indigestion caused by excessive consumption, or loose bowels and pain triggered by stressful situations.

Your GP is there to help navigate the maze of the healthcare system, detect patterns in symptoms, examine, conduct initial investigations and refer when appropriate. Many patients assume that every visit to their doctor with a gut-related problem will result in their GP slipping on a pair of rubber gloves and inserting a finger into one of the most intimate parts of our bodies. Rectal examinations are not comfortable; however, they are an important part of the medical examination and are only done when it is absolutely necessary. GPs are professionals and despite attempts to demystify the medical language, privacy, confidentiality and respect are three key elements of the role.

A diagnosis can dramatically improve quality of life compared to symptoms being ignored. GPs want to hear about recurrent blood seen in your poo, weight loss,



⁵ Research carried out by Mortar London, which conducted an online survey among 2,079 respondents across the UK and Republic of Ireland (1829 UK/250 ROI) between 7th and 10th August 2018.

tiredness, a persistent change in the frequency, colour and/ or consistency of poo and any other changes in bowel habit, as the sooner they know the sooner they can consider what action needs to be taken.

The GP consultation is short, so it is useful to make a list of the main symptoms you have been suffering from, when they started, anything that might have triggered them, any lifestyle changes you have made as a result of them, and any medication you may have tried from a pharmacist or shop. Expect to have your tummy examined (this isn't *always necessary) so wearing loose fitting clothes that can* be adjusted easily can be helpful. Blood tests are the main investigations that GPs carry out, although requesting a poo sample to check for infection or inflammation is often done. There is not an easy way to do this, and it is a messy process, but your GP may be able to suggest ways to make it more straightforward. It is unlikely that your GP will be able to make a diagnosis from a single visit, and they may refer you to hospital for further investigations such as an ultrasound scan, a colonoscopy (where a camera is inserted into your gut through your anus), or to see a gastroenterologist. If they think that cancer is a possibility, they can refer you urgently to be seen or to have a test within two weeks.

Once a diagnosis has been made there are many patient support organisations who can provide information: Guts UK, Crohn's and Colitis UK, Coeliac UK and Macmillan are just a few. Websites such as NHS.uk, and patient.info have links to many more.

Don't be afraid to speak to your GP – gut health problems are common, most people have had something at some point in their lives, and they are something we should all talk about more freely #GutTalk." We've also put together some practical tips on what to do before and after your GP appointment to make the most of it.

- Prepare: Make a note of symptoms and questions you'd like to discuss with your GP ahead of your visit. This will ensure you mention everything you need to and help ease nerves. A Food & Symptoms Diary, such as that on the Love Your Gut website or the IBS Network Symptom Tracker, can be a useful way to track any link between foods and symptoms and you can share it with your GP at your appointment. The Love Your Gut Digestive Health Assessment can help identify gut health issues and symptoms, ready to discuss with your GP.
- Get Support: If you'd feel more comfortable, ask a friend or family member to come with you to your appointment.
- After Your Appointment: Ensure you know when test results are due and chase them up if needed. Attend future appointments and book another GP appointment if you need to.



#GutTalk ... With Friends and Family



Gut health issues affect almost every aspect of daily life, including social life and relationships. Indeed, 91% of those suffering with gut health issues say their symptoms affect their social life and 88% say it affects their personal relationships⁷.

Although talking about gut health with friends and family can be embarrassing, doing so

will not only help them understand your condition, but will also help ease any stress you may feel about your symptoms.

Below, **Dietitian Jo Travers** provides her top tips on talking to friends and family about digestive health issues.

- **Explain how your symptoms affect your life:** Letting people know that your condition can affect the things you can do or eat helps them understand the impact your digestive health can have. Once they understand, they will realise why plans might need to change. If your friend suggests going for a pizza but it always makes you bloated for example, you could say, "Pizza doesn't agree with me, I find it hard to digest and I always feel horrible afterwards. Could we get something else to eat?"
- Don't feel you need to overshare: Explaining specific symptoms can feel uncomfortable but keeping it general and saying you have 'digestive problems' or sharing the name of your condition will provide the information people need without you having to get too personal. If a friend asks why you cancelled plans for example, saying something like, "My gut was playing up and I felt really unwell" answers the question, as well as offering further discussion if that's what you want.

- Talk to people ahead of time: Digestive symptoms can be unpredictable, so talking to people in advance means they will know what to expect and saves you the trouble of explaining when you aren't feeling well. If you are open and honest with your friends ahead of time for example, they are likely to be much more sympathetic if you have to cancel plans.
- Don't pretend everything's fine: If your gut health is affecting your work or home life, pretending it isn't is only going to add more pressure to an already difficult situation. Stress can make symptoms worse and trying to hide your symptoms can mean stepping into a vicious circle. If you catch yourself saying, "I'm fine" when someone asks, have a think if that's actually true! If it's not, saying something like, "actually I'm not great at the moment. My tummy is playing up a bit just now." Being honest can relieve some of the stress.

Know that you are not your bowel symptoms! Your gut health does not define you, but during a flare-up it can sometimes feel like it does. Don't feel like you have to "make up for" your symptoms. Trying to achieve too much when you are unwell can make you feel worse, so it's ok to tell people when you can't manage something. Say confidently, "I can't do that at the moment but when I'm feeling better I will be able to."



⁷ Guts UK (formerly Core): findings from research with patients, caregivers, and stakeholders, April 2017

#GutTalk ... At Work



Dealing with a gut health issue at work can be distressing - indeed, 29% of those experiencing gut health issues agree that their condition has a high or very high impact on their working life ⁸.

You may feel awkward, embarrassed or humiliated when explaining your condition to your line manager or colleagues, but it could help alleviate some of your anxiety if

you explain your condition with a trusted manager. They cannot support you if they do not know. Alison Reid, CEO, The IBS Network shares tips on talking about digestive health at work to colleagues and managers.

Stress and anxiety

Try:

- To manage your workload effectively.
- To pace yourself and not to be influenced by others' agendas.
- To make sure you take breaks.
- Talking to your line manager about your condition ask for support, do not keep it a secret!
- · Maintaining a regular schedule.

Travelling to work

Try:

- To ask about flexible working so you miss rush hour traffic.
- To be aware of where the public toilets are on your way to work and get a RADAR key if necessary to access them.

Diet and eating at work

Try:

- Getting up earlier to allow time for breakfast.
- Taking a proper lunch break and avoid eating meals on the run.
- Preparing your own food so you know what it contains.
- Not skipping meals to avoid having to go to the toilet.
- Drinking at least eight glasses of non -caffeinated fluids per day.

Be prepared

Keep a supply of any medication you use, along with some wipes and anything else you think you might need, like spare underwear, together in a bag within easy reach.

Employers

Consider:

- Creating an open culture to allow issues to be discussed.
- Flexible/different working hours.
- Allowing work stations to be moved nearer to a toilet.
- Allowing time off for medical appointments.
- Providing a car parking space near to the work entrance.

For those with IBS see The IBS Network's IBS Self-Care Programme and their guide to Managing IBS at Work.



⁸ Guts UK (formerly Core): findings from research with patients, caregivers, and stakeholders, April 2017

#GutTalk and ... Looking for Love

Looking for love can be difficult and scary for everyone, including those with gut health issues. To help you on your way, we've put together some dos and don'ts, as well as some help and advice for partners of those with digestive issues.

When you are looking for love

Dos

- ✓ Most people find meeting new people hard, but just get out and about and start meeting people!
- When trying to decide what to do for a date, choose an activity that doesn't stress you out.
- ✓ If you need to, make sure you take a change of underwear and any medication that you need with you when going on a date and research where the nearest toilets are beforehand.
- ✓ Be upfront and honest about symptoms and conditions when on a date.
- ✓ Before you tell your partner about your condition, practice what to say. This will ensure you feel ready and prepared to talk about it when the time is right. You can even practice with a friend!
- Choose the right moment, to tell them a neutral space and when you both feel relaxed is best.
- ✓ When it comes to rejection, remember that if someone can't live with your condition, they are rejecting that condition, not you. Keep going to find your true match!

Don'ts

- Put yourself in a position that you don't feel comfortable in.
- × Overdo it be realistic about what you can do.
- Co out for a meal if food will disagree with you choose something else to do such as bowling or going to the cinema.
- × Let one bad experience put you off.
- × Waste your time on someone who doesn't understand your issues.
- Explain your symptoms or condition on a first date

 get to know each other first and see if you feel
 the relationship could go anywhere.

Advice for partners

- Be mindful that your date might not find it easy to go out for a meal or drink alcohol. Suggest going for a walk in the park, going to see a film or listening to music instead.
- When your date talks to you about their condition, be interested, but not too inquisitive in case they feel uncomfortable.
- As with all relationships, take things slowly and respect your boundaries.
- Be flexible and understanding. Sometimes your date may have to cancel or change plans at the last minute and were probably looking forward to your date as much as you were! Suggest an alternative activity or reschedule.
- Be honest about your fears or concerns.



#GutTalk ...Advice for friends and colleagues

Because people still don't talk about their digestive health very often, we don't get a lot of practice at it and you may feel like you don't know what to say when people do want to talk to you about it. Really however, talking about gut problems should be as

easy as talking about a headache and below **Jo Travers**, **Dietitian**, shares tips to help you talk with others about their gut health issues.

Be compassionate. Any symptom that makes someone feel unwell will be impacting on their life. Showing that you care can relieve some of their burden and sometimes that can be as simple as saying, "let me know if you need anything".

Don't push your advice. IBS is a very individual condition and what works for one person, may not work for another. Although you may want to help and offer advice, don't force it. If you want to pass on something that you feel might help, saying something like, "I have heard that ... can help but I know the condition is different for everyone".

Don't ask for too much detail. If someone has opened up to you about their gut health, let them be in charge of how much detail they give you. They may not be ready for lots of questions about their symptoms. If you want to show you are interested and approachable you could say something like, "That must be tricky for you". This allows for more detail if they are ready to give it, but can also be answered with a simple yes or no.

- Prepare to be flexible. Sometimes gut health issues can be unpredictable, even when people have been managing their triggers well. You may find that if someone has a flare up of symptoms, they may need to change plans you have made at the last minute. While this may be inconvenient for you, it is likely to be far worse for them! Saying "Not to worry, let me know when you are feeling better" shows them support and lets them know you are ready to reschedule when they are.
- Change the culture. It only takes one person to take the first step in changing the cultural silence around gut health. Be this person! If you know someone who you think is suffering in silence let them know they can talk to you. Start the conversation by talking about your own gut health. Most of us have had digestive symptoms at some point, after all.





#GutTalk Glossary

Bowel, commonly referred to as: insides.

The bowel is made up of the small bowel and large bowel (the colon and rectum). Here, food is broken down and nutrients and water are absorbed. Waste is also stored in the rectum until it is passed out of the body.

- Bowel Cancer: Bowel cancer is a general term for cancer that begins in the large bowel. Depending on where the cancer starts, bowel cancer is sometimes called colon or rectal cancer. Bowel cancer is one of the most common types of cancer diagnosed in the UK. Most people diagnosed with it are over the age of 60⁹.
- Coeliac Disease: Coeliac disease is a common digestive condition where the small intestine becomes inflamed and unable to absorb nutrients. It can cause a range of symptoms including diarrhoea, abdominal pain and bloating. Coeliac disease is caused by an adverse reaction to gluten, a dietary protein found in 3 types of cereal: wheat, barley and rye¹⁰.
- Constipation, commonly referred to as: being blocked up, bunged up, congested.

Constipation refers to difficulty opening the bowels or passing stools. People diagnosed as constipated will generally open the bowels less than three times per week, feel the need to strain and/or pass hard stools. Whilst common, constipation rarely causes long-term problems and can generally be treated quickly and effectively.

- Crohn's disease: Crohn's disease is a lifelong condition in which parts of the digestive system become inflamed. It's one type of a condition called inflammatory bowel disease (IBD)¹¹.
- Diarrhoea, commonly referred to as: the runs. The term diarrhoea is used when stools are passed more than three times a day and become loose or watery. Acute diarrhoea refers to symptoms which come on suddenly and clear within 5-10 days, but if you're experiencing more persistent problems such as dehydration, visit your GP.
- Diverticular disease and diverticulitis:

Diverticular disease and diverticulitis are related digestive conditions that affect the large intestine (bowel). Diverticula are small bulges or pockets that can develop in the lining of the intestine as you get older. Most people with diverticula don't get any symptoms and only know they have them after having a scan for another reason. When diverticula cause symptoms, such as pain in the lower tummy, it's called diverticular disease. If the diverticula become inflamed or infected, causing more severe symptoms, it's called diverticulitis. You're more likely to get diverticular disease and diverticulitis if you don't get enough fibre in your diet¹².

Faeces, commonly referred to as: poo, number two. Waste matter remaining after food has been digested, which is then discharged from the bowels.





⁹ www.nhs.uk/conditions/bowel-cancer/

¹⁰ www.nhs.uk/conditions/coeliac-disease/

¹¹ www.nhs.uk/conditions/crohns-disease/

¹² www.nhs.uk/conditions/diverticular-disease-and-diverticulitis/

#GutTalk Glossary (Continued)

Gut, commonly referred to as: stomach, belly.

The gut (gastrointestinal tract) is the long tube that starts at the mouth and ends at the back passage (anus). The gut processes food from when it is eaten until it is either absorbed by the body or passed out as stools. The process of digestion begins in the mouth and continues onto the stomach and small intestine. It continues in the large intestine where fermentation of nondigestible carbohydrates (fibre) by microbiota takes place. Food that can't be digested, waste substances, germs and undigested food are all passed out as faeces.

- Heart burn, commonly referred to as: indigestion, reflux. Heart burn and acid reflux are the same thing and can cause a painful burning sensation in the chest. It occurs when food or drink travels back up from the stomach and into the oesophagus. In most cases, there seem to be no obvious causal factors although eating an excess of rich, fatty foods can have an effect as can excess weight.
- Indigestion, commonly referred to as: reflux, upset stomach, gas. Indigestion can be hard to define but is best described as unpleasant or even painful sensations in the top of the abdomen or lower part of the chest, which usually come on after eating or drinking. Although unpleasant, indigestion is rarely serious, but if indigestion develops for the first time in mid or later life or is persistent, you should contact your GP.

- Irritable Bowel Syndrome (IBS): Irritable bowel syndrome (IBS) is a common condition that affects the digestive system. It causes symptoms like stomach cramps, bloating, diarrhoea and constipation. These tend to come and go over time, and can last for days, weeks or months at a time. It's usually a lifelong problem. It can be very frustrating to live with and can have a big impact on your everyday life. There's no cure, but diet changes and medicines can often help control the symptoms. The exact cause is unknown it's been linked to things like food passing through your gut too quickly or too slowly, oversensitive nerves in your gut, stress, and a family history of IBS¹³.
- Inflammatory bowel disease (IBD):

Inflammatory bowel disease (IBD) is a term mainly used to describe two conditions: ulcerative colitis and Crohn's disease. Ulcerative colitis and Crohn's disease are long-term conditions that involve inflammation of the gut. Ulcerative colitis only affects the colon (large intestine). Crohn's disease can affect any part of the digestive system, from the mouth to the anus. People of any age can get IBD, but it's usually diagnosed between the ages of 15 and 40. There are also some less common types of IBD, which you can find out about on the Crohn's and Colitis UK website¹⁴.

 Ulcerative Colitis: Ulcerative colitis is a longterm condition where the colon and rectum become inflamed. The colon is the large intestine (bowel), and the rectum is the end of the bowel where stools are stored. Small ulcers can develop on the colon's lining and can bleed and produce pus¹⁵.



³ www.nhs.uk/conditions/irritable-bowel-syndrome-ibs/

¹⁴ www.nhs.uk/conditions/inflammatory-bowel-disease/

¹⁵ www.nhs.uk/conditions/ulcerative-colitis/

Other Love Your Gut Resources

For more Love Your Gut advice and information see our:

- Online Health Assessment www.loveyourgut.com/the-digestive-health-assessment/
- Food & Symptoms Diary www.loveyourgut.com/resources/food-and-symptoms-diary-2018.pdf
- Information Pack www.loveyourgut.com/help-and-resources/love-your-gut-information-pack/
- Exclusive recipes www.loveyourgut.com/getting-gut-healthy/recipes/
- Facebook Discussion Group

www.facebook.com/groups/675385549491650/

- Cookery School Tips www.loveyourgut.com/getting-gut-healthy/cookery-school-tips/
- 'What is your Gut telling you?' video www.youtube.com/watch?v=Czte9hVZejM



For more information

Love Your Gut partners



Guts UK Charity is the only national charity that fights all diseases of the gut, liver and pancreas – collectively known as 'digestive diseases'. They provide expert information, raise awareness of digestive health and fund crucial research into diseases of the gut, liver and pancreas. **www.gutscharity.org.uk**



The Bowel Disease Research Foundation (BDRF) funds high quality, practical research which improves treatment and survival rates for bowel disease patients across the UK. Founded by some of the country's leading colorectal surgeons, in recent years we have committed over £2 million to support research into all forms of bowel disease – principally bowel cancer and IBD, as well as conditions like faecal incontinence. A full list of the work we support is available at **www.bdrf.org.uk**



The Primary Care Society for Gastroenterology (PCSG)

is the voice of Primary Care Gastroenterology. We have a (mainly) GP membership and offer advice and guidance on gastrointestinal matters, as well as lobbying and influencing. We hold scientific meetings and have a bi-annual journal 'The Digest'. To find out more visit **www.pcsg.org.uk**

Bowel & Cancer Researc **Bowel & Cancer Research** is a registered charity. We fund the best science in bowel cancer and other bowel diseases anywhere in the UK and invest in the next generation of experts with support for PhD students. We involve patients, their loved ones and carers in ours and our partners' research and work to challenge taboos and break down stigma.

See www.bowelcancerresearch.org



St Mark's Hospital Foundation funds research, education & dissemination of clinical excellence at St Mark's Hospital, a world-leading bowel disease specialist. Founded over 180 years ago, St Mark's is a national referral centre for complex bowel disease cases seeing over 50,000 patients annually from across the UK. St Mark's vision is of a future free from the fear of Bowel Disease. See www.stmarkshospitalfoundation.org.uk

The IBS Network is the national charity supporting people living with Irritable Bowel Syndrome. Our mission is to provide information, advice and support and to work alongside healthcare professionals to facilitate self-care. See www.theibsnetwork.org

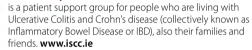
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Irish Nutrition & Dietetic Institute (INDI) was founded in 1958 and is the professional organisation for dietitians in Ireland, representing over 700 members who work in many areas of healthcare. www.indi.ie

Irish Society for Colitis and Crohn's Disease (ISCC)



Irish Practice Nurses Association (IPNA) is a professional membership association of Practice Nurses. The main objective of the association is the advancement of education in general practice in Ireland. www.irishpracticenurses.ie

Love Your Gut and Love Your Gut Week is an initiative of Yakult UK and Ireland in association with our UK partners: Guts UK, Bowel & Cancer Research, St Mark's Hospital Foundation, The IBS Network, Bowel Disease Research Foundation and the Primary Care Society for Gastroenterology; and Irish partners the Irish Nutrition & Dietetic Institute, Irish Society for Colitis and Crohn's Disease and the Irish Practice Nurses Association.

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