

# 11 things you shouldn't say to someone with bowel problems



## You don't look sick

It is one of the most difficult things about having an intestinal disease - the disease is rarely visible on the outside. People don't realize that you may have used your last resources to shower, get dressed, get your hair done and get out the door.



## You need to change your diet

Patients explain that they receive unsolicited advice about their eating habits, such as "If you ate better, maybe you wouldn't have problems with your illness" and "why are you sick all the time? Maybe you should take vitamins and supplements." Although food can affect the symptoms of a disease outbreak, there is no evidence that diet causes inflammatory bowel disease or is the cause of disease outbreaks. However, it is important for people with intestinal diseases to eat as healthy and balanced a diet as possible - which they probably already know.



## Can you tolerate eating that?

There is no universal diet plan for intestinal disease. Fruit and vegetables can be bad for some, and others are fine with spicy food. Food affects people individually. You have to try yourself out using the exclusion method, everyone has to individually deduce what works and what doesn't work. Intestinal patients usually know what they can eat, if someone comments on their food it becomes a bit awkward.



## You must have a lot of stress in your life

Many people mistakenly believe that stress causes inflammatory bowel disease. There is absolutely no evidence that stress or tension causes bowel disease, although stress can make symptoms worse for people who have the diseases. Crohn's and colitis are autoimmune diseases, which means that the immune system attacks the intestinal tissue.



## I know how you feel

When people with intestinal diseases tell someone about their condition, they often learn a lot about the person's digestive problems.

It is probably better to keep information about your bowel and stomach problems, diarrhea or irritable bowel syndrome to yourself.

Don't say you understand how they feel unless you feel it yourself - otherwise you won't know.



## You've lost weight! You look good!

"What annoys me the most are comments about my weight and other weight-related things," says one patient. She talks about the time her mother, who also has colitis, had lost around 25 kg. People kept saying how good she looked. I thought instead. "No, she doesn't look good. Her skin hangs and her face is colorless. We are so focused on the weight that we don't notice anything else," she says.



## Why are you so tired?

People need to understand that intestinal diseases can be serious diseases. If you can't attend an event or if you have to stay home from work, it's not because you're lazy - it's because you're sick. Gut sufferers hate it when their friends and family try to get them to do things, they can't handle by saying "oh come on. You can't be that tired, can you?" Intestinal sufferers often answer them by saying "if you've lost as much blood as I do every time I go to the toilet, you'd be pretty tired too."



## Come on, take a bite!

Many people with intestinal diseases are, of necessity, very aware of which foods they should avoid. A patient says that he gets annoyed when people ask him why he eats the same thing every time they go out. "You definitely have to listen to your body," says another patient and says that she has done much better by figuring out which foods are ok for her to eat instead of listening to general advice. "Don't let anyone dictate to you."



## You have really gained weight!

Adrenocortical hormone is one of the most effective medications that can suppress an outbreak of the disease in the short term. But it has numerous side effects, including weight gain. Another side effect is water retention in the body, which can lead to a "moon face", where the cheeks become rounded. This can give the impression that a person is fat, even if the body is slim.

Fortunately, this side effect disappears when you stop taking the medicine. Until then, it is best to refrain from commenting on appearance or weight at all.



## Can you wait until the next exit?

Assume the answer is no.

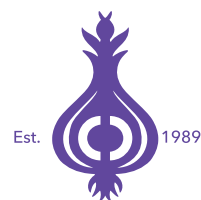
If you're sitting in a car with a colicky person and they tell you they need to go to the bathroom, listen to them. A great fear that many intestinal sufferers have is being stuck in traffic. Help them find the nearest toilet and get them there as quickly as possible. Another question you shouldn't ask is: "Why can't you just hold on?"



## You are so lucky - you can eat anything and stay thin!

Well, not really. Weight loss often occurs due to outbreaks that cause severe intestinal pain and bloody diarrhea that can mean spending most of the time in the bathroom.

During an outbreak, it may be necessary to choose your foods carefully so that they do not aggravate the symptoms.



COLITIS - CROHN FORENINGEN  
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## CCF - patient association for bowel disease

If you are under investigation, have received a diagnosis, are a relative or simply have an interest in supporting or gaining knowledge about bowel diseases, you are most welcome.

At CCF, you can get good advice and exchange experiences with like-minded people, receive free help from CCF's social worker or bowel counselors.

CCF has created more than 25 Facebook groups.

The official FB: <https://www.facebook.com/groups/colitis.crohn/>

Instagram: colitis\_crohn\_foreningen

You have the option of a personal membership, a family membership and a business - support membership.

As a member, you receive, among other things:

- CCF's popular magazine four times a year
- A membership card that also functions as a toilet card
- Participate in CCF's courses, e.g. youth, adult, and children/youth & parents course
- Can receive free of charge CCF's information booklets about, among other things intestinal diseases and nutrition for you with IBD etc.
- Participate in the local branches' lectures, for example on research and nutrition, as well as other member events
- CCF collaborates with the Sunflower Programme, which focuses on invisible disabilities. "The key words are: More time, patience and help"

If you wish to support CCF with a gift contribution, this can be done either via our webshop: [www.ccf.dk/shop/bidrag](http://www.ccf.dk/shop/bidrag), or by paying directly to: Registration number. 1551 - Account no.: 4 666 666. The gift contribution is deductible if you provide your social security number when making the transfer; and all are welcome and appreciated.

Read more about CCF at [www.ccf.dk](http://www.ccf.dk)



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BREAK THE TABOO

"Around 1 million Danes live with an intestinal disease"

YOU'RE NOT ALONE!

In this pamphlet you get a small insight into the most common intestinal diseases.

Here you also see 11 things you should not say to someone with bowel problems.

[www.ccf.dk](http://www.ccf.dk)



## Crohn's disease & ulcerative colitis INFLAMMATORY BOWEL DISEASE (IBD)

These two chronic intestinal diseases are autoimmune diseases, i.e. that the immune system, in addition to taking care of the normal and vital functions, also attacks the body's tissues.

The diseases are characterized by the fact that an inflammatory state occurs in the intestines. In Ulcerative Colitis, only the mucosal layer of the large intestine is attacked, while in Crohn's disease the entire intestinal wall can be affected and the inflammatory changes can attack both the small intestine and the large intestine. Just as in rare cases there can also be inflammation in the esophagus and stomach.

It can sometimes be difficult, despite thorough investigations, to determine which of the two diseases is involved. However, this will rarely affect the medical treatment, which will very often follow the same principles regardless of which of the two diseases you suffer from.

Fortunately, different medical treatment can be given, depending on the severity of the disease and/or whether there is an acute outbreak of the disease or it is a quieter period.

Most patients must be on life-long medical treatment, in order to keep the disease at bay as far as possible.

You typically go through several different examinations both in connection with establishing the diagnosis, but also in connection with later follow-up.

You will typically be associated with an outpatient clinic with specialists in treating Crohn's disease and ulcerative colitis. Typically, you will have ongoing blood tests, deliver stool samples for examination for bacteria and inflammation, as well as various X-rays, ultrasound scans and binocular examinations of the intestinal system.

It is all planned in collaboration between you, as a patient, and the treatment team.

### Crohns disease

In many cases, the disease is in the lower part of the small intestine, but it can be located in all parts of the intestinal system.

Prolonged diarrhea. Not everyone gets diarrhea. Some may have normal stools, while others may become constipated (constipated).

Crohn's disease can cause abscesses, fistulas and "tags" (small flaps of skin/ polyps at the rectum).

Growth and development problems and poor well-being. Seen primarily in children.

If medical treatment fails, surgery can be performed. The nature of the operation is determined by which section of the intestine is affected and how widespread the disease is. Typically, the diseased piece is removed and the bowel ends are then sewn together. In some cases, it is necessary to create a stoma.

### Common denominators

Intestinal and abdominal pain.

Air in the intestines, bloated and distended intestines. acute urge to defecate, where there may be bloody and frequent stools (diarrhea) with mucus and pus to a greater or lesser extent.

Nausea and possibly vomiting.

Decreased appetite and weight loss. in some cases, weight gain is experienced.

Fever.

Headache.

Blood and vitamin deficiency. general loss of nutrients.

Fatigue (combination of exhaustion, tiredness and lack of energy).

Haemorrhoids (small blood pockets near the rectum).

Joint symptoms (inflammation of smaller and larger joint muscle attachments to joints).

Challenges with teeth and gums. narrowing of the intestines.

Skin problems (approx. 5% experience getting rosacea, most often on the lower legs or arms). eye symptoms (iritis, uveitis or inflammation of the conjunctiva).

Spinal arthritis, where approx. 3-5% get inflammation localized in the spine and up to approx. 25% may have changes in the joints of the sacrum.

Approx. 2% experience inflammation of the bile ducts.

### Colitis

Colitis most often affects the rectum and the lower part of the colon, but the entire colon can be attacked.

There may be blood from the intestine between stools. Blood deficiency (anemia). Pain, which often subsides after going to the toilet.

Colitis will in most cases be characterized by short periods of activity and symptoms - and long periods when the disease is at rest and does not cause symptoms.

If the medical treatment is ineffective, you can have surgery for ulcerative colitis. The diseased intestine is removed, and either a small bowel stoma is subsequently fitted, or an operation is offered, in which a kind of artificial rectum (J-pouch) is made from the lower part of the small intestine, which is sewn to the rectal opening.

## Irritable bowel syndrome – colon irritable – irritable bowel IRRITABLE BOWEL SYNDROME (IBS)

It is expected that approx. 700,000 Danes today are affected by irritable bowel syndrome.

Irritable bowel syndrome is a diagnosis of exclusion. This must be understood as meaning that it must be ruled out that there are other problems requiring treatment in the intestinal system. This is usually done on the basis of blood samples and stool samples. Sometimes it may be necessary to do supplementary binocular examinations and X-ray examinations.

Irritated colon is thus characterized by its symptoms and not by the occurrence of detectable changes in the intestine.

Depending on what the dominant symptoms are, there are different options to improve the condition. It can, for example, concern advice regarding diet and lifestyle, laxatives and sometimes also medicine, which can work either against diarrhea or constipation, depending on the nature of the problem.

The symptoms usually consist of a combination of the following:

Bloated stomach that rumbles. Loose stools. Constipation (constipated). Alternating bowel patterns, periods of either diarrhea or constipation or both at once. Air and odor nuisances. Intestinal and abdominal pain, which may be relieved by defecation. The pain can come as attacks, and they will most often sit down on the left side.

There is so much variation between what patients with irritable bowel syndrome can tolerate eating that it is very difficult to give general advice. You have to try yourself. Some hospital outpatient clinics have the option of referring to a dietician and this may be a good idea for some.








Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on its surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges (passed easily)
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces ENTIRELY LIQUID

Figure: The Bristol scale is a good indicator of bowel function, and it can be a support for getting an overview of your stool patterns.

## Bile acid malabsorption GSM – BILE ACID DIARRHEA

Bile acid metabolism problems are due to a lack of absorption of bile acids in the lower part of the small intestine. It is only here that the recording takes place.

Problems with the bile acids show up as diarrhea. The causes of disturbances in bile acid metabolism can be disease in the lower part of the small intestine, including: Crohn's disease, following surgery with the removal of a piece of small intestine, radiation-damaged small intestine, diabetes, gallstone surgery and unknown causes.

It is not a malignant disorder, but it can be inhibiting for daily function due to the symptoms that can accompany it in varying degrees.

The diagnosis is made by a scan called SeHCAT, which involves swallowing a capsule containing a small amount of harmless radioactive tracer, which the intestines will absorb and be excreted again. Three hours after ingestion, the stomach region is scanned and seven

days later, the scan is performed again and the result should be available. However, it is not a routine everywhere to apply this study. Sometimes it is assessed whether a treatment aimed at the condition has an effect. The treatment consists of agents that bind bile acids in the intestine. A Danish study has shown the effect of a drug used in the treatment of diabetes (Victoza). However, this treatment is not yet standard and requires daily injections of the drug. So far, the treatment is therefore reserved for particularly stubborn cases.

**Symptoms:**  
Chronic watery diarrhea  
Frequent toilet visits  
Fatigue  
Abdominal cramps  
Flatulence (farts)



At [www.ccf.dk](http://www.ccf.dk) you can find more information about the intestinal diseases, other related intestinal diseases, possible sequelae and consequences of having an intestinal disease. If you have, or may be on your way to, CCF would recommend that you seek more information from COPA, which is the patient association that specializes in that area.

You can find them at:  
[www.copa.dk](http://www.copa.dk) or  
[www.stomiguiden.dk](http://www.stomiguiden.dk)  
(which is particularly targeted at young people with a stoma).

## Microscopic colitis

Microscopic colitis is a collective term for various chronic and benign colon inflammations, which often first affect patients over 60 years of age. The most important diseases in this group are collagenous colitis and lymphocytic colitis. The diagnosis is made by binocular examination of the colon, where tissue samples are taken from the colon's mucosa. The colon will most often see looks completely normal, but colitis can be detected by microscopy of the tissue samples.

The condition sometimes resolves on its own, so treatment with medication may sometimes be unnecessary. Sometimes stopping agents such as Imodium can be sufficient. Some have such severe diarrhea that medical treatment will be offered treatment in the form of a special adrenal cortex hormone preparation, which has the advantage that after working in the gut it is inactivated in the liver, which reduces the amount of side effects.

Living with a bowel disease can be challenging. People with these serious diseases can lose weight during an outbreak and gain it all back - and then some - if they, for example, must take adrenocortical hormone to get the symptoms under control. It can also be difficult to find food that is suitable to eat, because the condition can be individually determined. Against this background, there are therefore some comments - such as those that focus on appearance, weight and diet - that can be more harmful than helpful.

**Common symptoms for these "colitis":**  
Diarrhea  
Fatigue  
Large amounts of stool  
Often bloated with slight intestinal and abdominal pain



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