



..... Living a good life .....  
**with ulcerative colitis**

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The glossary contains important medical terms in connection with ulcerative colitis. These are bold in the text.

# Dear Patients,

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You were diagnosed with “**ulcerative colitis**”.

You are probably wondering what this disease means to you, and whether and how your life will change as a result of it.

Even if **ulcerative colitis** may accompany you throughout your life, do not let your life be determined by the disease! You, your treatment team and a therapy suitable for you can reduce the symptoms to such an extent that you live with your disease, integrate it into your personal and occupational everyday life, and thus can positively influence the course of the disease.

With this brochure, we would like to provide you with an overview of the disease, treatment options and influence of **ulcerative colitis** on your partnership and occupation, which may serve as a basis for discussing further, concrete questions with your treating medical team.

**Dr. med. Lars Konopka**  
Internist/Gastroenterologist



# What is ulcerative colitis?

**Ulcerative colitis** is a chronic inflammatory bowel disease that, unlike Crohn's disease, exclusively affects the large intestine and can occur at any age. Disease arrest is called **remission**. A renewed outburst is called a **flare-up**.

## Central symptoms of ulcerative colitis are:

- **Inflammation of the large intestine**
- **Possible bowel dysfunction:** mucous and more frequent (4 times and more often during the day), watery, partly bloody bowel movements

## Possible consequences are:

- Pain and cramps in the stomach or lower abdomen
- Diarrhoea
- Tiredness and fatigue (chronic tiredness)
- General malaise
- Loss of appetite and weight loss

**Good to know:** The **immune system** is our body's own defence system. It protects the body from foreign bodies, such as **bacteria, viruses, fungi** or **parasites**, which can cause diseases. Immune defence usually takes place according to a specific process (**immune response**). This defence mechanism is impaired in patients with **ulcerative colitis**. The immune system that is now too active intensifies the inflammatory reaction, and the typical **ulcerative colitis** symptoms occur.

So far, it is unclear how ulcerative colitis develops. However, various factors seem to play a role:



Diet



Drugs



Smoking



Genetic predisposition



Microbiome



Appendectomy



Hygiene

### Different involvement patterns of ulcerative colitis:



Proctitis



Proctosigmoiditis



Distal colitis



Extensive colitis



Pancolitis

Different types of **ulcerative colitis** are differentiated depending on which part of your **large intestine** is affected. The inflammation always starts in the rectum, the end section of the large intestine, and spreads continuously from there into the **colon**, the section above the rectum and the longest part of the large intestine.

### How is ulcerative colitis manifested?

Ulcerative colitis is manifested differently in all those affected. The type of symptoms often depends on the location of the inflammation in the colon. The severity (e.g. frequency of toilet visits) can also vary from patient to patient. Symptoms can recur throughout life, but may also disappear again. Various treatment options can help you to alleviate your symptoms.

Use the questionnaire at the end of the brochure, and write down before your doctor's visit what symptoms you have and how severe they are. This will allow your doctor to better support you in choosing the right therapy.

## What are extraintestinal manifestations (EIM)?

**Ulcerative colitis** can also lead to various symptoms outside your digestive tract. These symptoms are called **extraintestinal manifestations (EIM)**. These may include:

- **Arthritis:** Inflamed, swollen and painful joints
- **Problems with the skin:** Blisters, redness or other swelling of the skin
- **Inflammation of the eyes**
- **Inflammation of the liver and bile,** which may affect liver and bile function

## What do I need to know?

Also discuss the subject of colon cancer screening with your physicians, as the risk of colon cancer may be increased in patients with ulcerative colitis. Regular checks of the **intestine** (enhanced colonoscopy) help to keep an eye on the risk.



## My treatment options

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**Ulcerative colitis** may vary in all patients. Talk to your doctor about which therapy is best for you.

The goal of the therapy is to achieve long-term **remission**, alleviate your symptoms, and reduce the number of acute **relapses**. Various drugs are available for this purpose. In addition to treatment with medicines, small changes in your diet and/or lifestyle can also contribute to alleviating your symptoms.

The therapy tailored to you can also help you to live your normal everyday life, continue to practice your occupation, and pursue your leisure activities.

## In addition to other things, your treatment depends on the following questions:

- Which part of your **large intestine** is affected?
- Do you have symptoms outside your digestive tract (**EIM**)?
- How severe are your symptoms?
- Does your disease get worse at regular intervals?  
If yes, how often do you have **relapses**?

## Anti-inflammatory drugs

**Anti-inflammatory drugs** (so called 5-ASA-preparations) are often the first step in the treatment of ulcerative colitis. They can reduce the **inflammation** in your **intestines** are taken orally, but are also available as **enemas**, foam, or **suppositories**. The application depends on which area of your intestine is affected.

Another option is so-called **steroids** or **corticosteroids**. They alleviate inflammation by intervening in the **immune system** processes in a regulating manner. They are generally used over a short period of time, since they do not maintain remission.



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## Immunosuppressants/immunomodulators

**Immunosuppressants/immunomodulators** also regulate and normalise the **immune response**. Thus, they prevent excessive immune reactions from damaging the intestinal mucosa. They are used if the disease worsens, or if **steroids** do not work anymore or should no longer be used.

## Biologics/biosimilars

Another treatment option is drugs that are produced using biotechnology, so-called **biologics/biosimilars**. Among these, there are different active substance classes that suppress an overreaction of the immune system by intervening in one of the various processes of the body's own immune response. They can thus reduce **inflammation**. As a rule, people who suffer from severe ulcerative colitis or who do not respond to other medications or do not tolerate them are treated with these drugs.

Sometimes various medications are used simultaneously. In some patients, this leads to better efficacy than with individual drugs.

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# Living well with ulcerative colitis

## Diet

There is no special diet, since **ulcerative colitis** progresses very differently in all those affected. Now it's time to get your cookpot and find out what you like and what is good for you. Eat as many different foods and nutrients as possible so that your body gets enough energy and you maintain your weight, i.e. with many vitamins, minerals and trace elements. We have put together a few simple tips for you.

Eat approx. **6 – 7 small meals** distributed throughout the day.



**Too fat?** Take sour cream or milk if you don't tolerate sweet cream.

**Just try it out:** Eat foods that you think do not suit you only one at a time. If symptoms occur within one day, these foods should be omitted.



**You don't have to completely avoid muesli** either; often individual types of grains are not tolerated. Or try **alternatives such as quinoa or porridge**.

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**Better off without it:** Fried and fatty items such as chips, smoked or breaded meat items such as Viennese schnitzel. Food that is too seasoned, too hot and too cold is usually not well tolerated.



**Too spicy?** Shallots are milder and more digestible than onions; use cooked garlic instead of raw.

**Take your time eating** and chew everything thoroughly; this means less work for your bowels, and they can absorb nutrients more easily.



A high-fibre diet can cause flatulence and abdominal pain. **Better:** eat soft, easily digestible products such as toasted bread, mixed-grain bread, light rolls, fine bread without grains, compote/mashed fruit, soups. When it comes to fruit, vary and test which type of fruit you like best.

Write a **food diary** about which foods you tolerate well and which you do not tolerate.



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## Diet

### What can I drink?

Also make sure that you drink enough. Healthy adults require 1.5 to 2 litres per day. Discuss with your doctor how much you should drink.

### The following are usually well tolerated:

- Non-carbonated water
- Unsweetened herbal teas such as chamomile, fennel, peppermint, lemon balm tea
- Low-acid fruit juice or ciders of apple, banana, peach, pear or grape juice
- Vegetable juice

### Drink less:

- Coffee or espresso
- Black tea

In general, you should avoid excessive alcohol consumption. You should completely avoid high-percentage alcohol because it can severely irritate the intestinal mucosa.



### What do I need to be aware of during a flare-up?

Acute **flare-ups** can lead to severe diarrhoea. Now it is particularly important that you consume enough fluids and nutrients.

During a **flare-up**, or if you are very underweight, it may therefore make sense to feed liquid food, for example via a stomach tube (enteral nutrition).

In the case of very severe complaints or significant malnutrition, there is also the possibility of providing appropriate nutrient solutions via the bloodstream (parenteral nutrition). This bypasses and protects the digestive tract.

### Good to know:

Discuss with your doctors what you can additionally do. Nutritional advice or, if necessary, nutritional therapy can also support you. Usually, health insurance companies pay a share of the costs.

## Pregnancy

Having a child is one of the most beautiful things in the world, and is also possible with **ulcerative colitis**. If you want to have children, talk to your doctor early on so that you can prepare everything for your pregnancy. If possible, plan your pregnancy in a phase without disease activity. The probability of giving birth to a healthy child is just as high during **remission** as for healthy persons.

And if there is no inflammation in the area of the anus or perineum, most pregnant women can give birth naturally, unless there are other reasons for a Caesarean section.

### Good to know:

The fertility of patients with **ulcerative colitis** generally does not differ from that of healthy persons. However, temporarily decreased fertility may occur after extensive small or large bowel surgery.

In men, treatment with sulfasalazine may temporarily reduce fertility, so treatment should be changed early enough. The same applies to the active substance methotrexate.

## Can I continue to take my medication?

Inform your doctor that you are or would like to become pregnant. They can then adjust your treatment if necessary. Remember to also discuss the therapy for breastfeeding with your physicians. If **relapses** occur during pregnancy, it is important to treat them to avoid complications.



## Partnership

You can also have a happy partnership and a fulfilling sex life with **ulcerative colitis**. For some patients, the disease is very stressful: Shame and uncertainty towards the partner, but also concerns about **disease relapses** or keeping one's job can have a negative effect on self-confidence and partnership.

It helps if you speak openly about your disease in the partnership – about what is stressful for you, or what needs and wishes you have.

### Good to know:

The effect of a contraceptive pill can be limited during a **disease relapse** because absorption of the active substance in the **intestine** is reduced. Therefore, it may be useful to switch to other methods of contraception such as a spiral, diaphragm or condom.



## Occupational life

A normal occupational life is often possible. Even small changes can be a big help, e.g. working from home or working where a toilet is readily available nearby. When it comes to choosing an occupation, the occupations in which working hours and breaks can be flexibly arranged are generally better suited.

Heavy physical work or tasks requiring uninterrupted attendance are generally less suitable. An important question is whether you tell employers and colleagues openly about your illness. This might have some advantages, e.g. fewer misunderstandings due to absences, frequent visits to the bathroom, or regular visits to the doctor, and fewer excuses. However, please consider that not all employers are sufficiently understanding of employees with a chronic illness.

**If you are severely restricted, you can apply to the pension office for severe disability. You will receive certain kinds of help or compensation for disadvantages, e.g. special protection against dismissal or parking aid.**

## Useful addresses

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### Kompetenznetz Darmerkrankung (Knowledge network for bowel diseases)

Here you will find information about the disease, treatment, and specialised physicians.

[www.kompetenznetz-darmerkrankungen.de](http://www.kompetenznetz-darmerkrankungen.de)

### Selbsthilfe Deutsche Morbus Crohn/Colitis ulcerosa Vereinigung (DCCV e. V.) [Self-help German Crohn's Disease/Ulcerative Colitis Association]

Inselstraße 1, 10179 Berlin, Germany  
Telephone consultation: 030 2000392-11  
[beratung@dccv.de](mailto:beratung@dccv.de)  
[www.dccv.de](http://www.dccv.de)

### Bundesverband Deutsche ILCO e. V. [Federal Association of German ILCO]

Thomas-Mann-Straße 40, 53111 Bonn, Germany  
Telephone: 0228 338894-50  
(Mondays to Thursdays from 9:00 a.m. to 3:00 p.m.)  
[info@ilco.de](mailto:info@ilco.de)  
[www.ilco.de](http://www.ilco.de)

You can find addresses for nutritionists at the Deutsche Gesellschaft für Ernährung e.V. (DGE) (German Association for Nutrition) or the Berufsverband Oecotrophologie e.V. (VDOE) (Professional Organisation for Oecotrophology).

This brochure cannot replace the professional advice of your doctors. For further information about your disease, please contact them.

## Glossary

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**Anaemia:** also known as blood deficiency; refers to a lack of the red blood pigment haemoglobin in the blood.

**Anti-inflammatory drugs:** anti-inflammatory medicines. They can influence the inflammatory process and thus control or improve inflammation.

**Arthritis:** disease in which the joints are inflamed, often associated with pain and swelling.

**Bacterium (plural: bacteria):** microorganisms (microbes), which belong to the living organisms. They are very small: Hundreds of thousands of bacteria fit into a point at the end of the sentence. Many types of bacteria live in your intestines and on your skin, for example, and ensure that you stay healthy. Other types of bacteria can cause diseases such as cholera or tuberculosis.

**Biologics:** Biologics are drugs with a complex structure and a high molecular weight that are produced biotechnologically, i.e. using biological organisms.

**Biosimilar:** Biosimilars are biological medications that are comparable to the already available first-supplier medication in terms of quality, safety and efficacy. For this purpose, the biosimilar is tested via a strict approval route.

**Colon:** also: large intestine; part of the intestine in which the stool develops. Here, water and nutrients that the body needs are absorbed and released into the bloodstream. This firms up the stool.

**Colonoscope (endoscope):** long, flexible tube with a camera.

**Colonoscopy:** a medical examination in which a colonoscope is inserted into the rectum. With the help of colonoscopy, doctors can see which parts of the intestine are affected by the disease.

**Endoscopy:** a medical examination in which an endoscope (see colonoscope/colonoscopy) is inserted into the mouth. Using the endoscope, doctors can see which parts of the intestine are affected by the disease.

**Enema:** introduction of a liquid via the anus into the intestine.

**Extraintestinal manifestation (EIM):** manifestation that occurs outside the intestine (intestinum).

**Fungus:** a living organism that can cause diseases in the body.

**Immune response:** immune system processes to prevent foreign bodies (bacteria, viruses, fungi and parasites) that could cause diseases.

**Immune system:** the body's own defence system against pathogens and foreign bodies. It includes many different organs and immune cells, which in turn produce signals to communicate with each other.



**Immunomodulators:** medicines that influence the immune response of the body. For example, they can help to prevent the immune system from attacking the intestines in ulcerative colitis.

**Immunosuppressants:** medicines that suppress the immune system.

**Inflammation:** the natural reaction of the body to injuries, infections or irritations. Normally, the affected body region swells, is reddened, hot and painful. These symptoms disappear when the risk of an infection is eliminated. If an inflammation is out of control or takes too long, it can also cause damage to healthy parts of the body.

**Intestine:** organ; part of the body that is responsible for making the vital nutrients available to the body from food.

**Parasite:** an organism that uses other organisms and removes water and other nutrients from its host. A tapeworm is counted as a parasite, for example.

**Perforation:** perforation or drilling of a wall of an organ such as the intestine.

**Rectum:** the end piece of the large intestine that opens into the anus. The stool is excreted here.

**Relapse or flare-up:** period in which the disease is active after the inactive phase.

**Remission:** period of time in which the disease is not active.

**Small intestine:** the part of the intestine between the stomach and the colon or large intestine. Most of the food is absorbed in this part of the intestine.

**Steroids or corticosteroids:** anti-inflammatory medicines.

**Suppositories:** possibility of non-oral administration of medication. Usually a small round capsule that is inserted into the rectum.

**Ulcer (or ulceration of the intestine):** tear or perforation in the intestinal wall leading to an open wound. It often takes a long time before it heals.

**Virus:** a small pathogen that cannot multiply independently, but only if it gains access to a host cell. Many viruses can cause diseases. Flu, hepatitis and AIDS are caused by viruses, for example. Viruses are even smaller than bacteria.

Complete this short questionnaire for your next doctor's appointment. Your answers can help to optimally adjust your therapy.

### 1. When did you have your last flare-up?

\_\_\_\_\_

### 2. Do you have new symptoms?

yes  no

Describe which: \_\_\_\_\_

### 3. How high is the number of bowel movements per day?

less than 4  4 – 6  more than 6

Bloody bowel movements:  yes  no

### 4. Is your urge to have a bowel movement increased?

yes  no

### 5. Do you have or have you had abdominal pain or cramps?

yes  no

### 6. Are you restricted due to your disease, and if so, in what areas?

- In occupational life
- In everyday life
- For leisure activities
- In your partnership

### 7. Do you have depressive moods or fears?

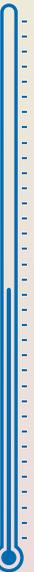
yes  no

### 8. Do you have problems taking your medication?

yes  no

### 9. Please mark on the scale how you feel today.

Sick/ill



Healthy



You can find further ideas for dealing with  
your disease on a daily basis here:

[www.hexal.de/patienten/feelinx](http://www.hexal.de/patienten/feelinx)



#### How to reach us:

You have important questions about our medicines,  
or you would like to order materials?

Call us toll-free at **0800 439 25 23!**

You can reach us from Monday to Friday  
**from 8:00 a.m. to 6:00 p.m.**

Please contact your doctor if you have any questions  
about your treatment.

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