

# Inflammatory bowel disease and family planning

— PREGNANCY, CHILDBIRTH, BREAST-FEEDING —



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The content is for general educational purposes only and is not a substitute for a visit to the doctor or a consultation with a pharmacist. It is important that you follow the instructions of your doctor and other healthcare professionals regarding your health condition or illness.



## Introduction to the brochure

When we get sick, the illness usually disrupts our daily routine. A chronic illness, such as inflammatory bowel disease (IBD), affects all aspects of our lives, since it changes our habits, relationships, work, pastime, and social network.

**It is very important for individuals with IBD to have access to correct information on the disease and its treatment. In cooperation with experts and our supporters, the Association of IBD aims to issue various publications for our members and broader public.**

IBD is a chronic, immune-mediated, lifelong illness that includes periods of exacerbation and improvement (*remissions*). IBD includes Crohn's disease (CD) and ulcerative colitis (UC). A smaller percentage of patients cannot be classified within these two forms; therefore, they are diagnosed with a non-classifiable IBD that may later progress to CD or UC.

The aetiology includes hereditary factors, immunologic factors, environmental factors, and the intestinal microbiome also plays a special role. IBD may occur at any age, from childhood to old age; however, it most commonly occurs in **young adults**, with peak incidence between 20 and 30 years of age. Therefore, our Society decided to issue a brochure on family planning in individuals with IBD (pregnancy, childbirth and breast-feeding), in cooperation with the physicians from the University Medical Centre Ljubljana, and Lek. The brochure is intended to help people with IBD who are planning to start a family, their partners, and closest persons.

In order to offer as professional and as comprehensive information as possible, Docent Dr. Gregor Novak, specialist of gastroenterology, and Asst. Vesna Fabjan Vodusek, specialist of gynaecology and obstetrics, helped us preparing this brochure and we are very thankful for their efforts.

One of the most important decisions in life includes parenthood; therefore, we hope this brochure will help you on your path of family planning.

Mateja Saje, the president of the IBD Association

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Planning and management of pregnancy in women with **inflammatory bowel disease (IBD)** is currently very similar to that in healthy females, since a better understanding of the disease and newer, safer medicines enable us to better control the underlying disease and achieve a better quality of life.

# Prior to conception

It is important to achieve remission of the disease without any significant symptoms or signs of inflammation.



## Can I get pregnant safely despite IBD?

For sure. Remission of the bowel disease is key for planning and managing a successful outcome of the pregnancy. Active illness is associated with an increased risk of a worse pregnancy outcome, e.g. miscarriage, preterm delivery, intrauterine growth restriction, and low birth weight.

Prior to the planned pregnancy, it is recommended to confirm remission by *endoscopy* (an examination of the digestive tract with a special instrument) or other objective examinations. It

is also recommended to check the **nutritional status**, and potential deficiency in vitamins, minerals, and iron which should be supplemented in this case.

Uncontrolled disease requires careful monitoring of the pregnancy by a specialist in digestive diseases (*gastroenterologist*) and a FMF specialist (a gynaecologist, specialised in The Fetal Medicine).

## Can IBD make getting pregnant more difficult?

**If IBD is controlled, the chances of women with IBD getting pregnant are comparable with the general population.**

The ability to get pregnant may be slightly compromised in females with active Crohn's disease. This may be the consequence of an active disease (e.g. painful intercourse due to the disease being active in the anal region – *perianal diseases* – or spreading of the inflammation to fallopian tubes/ovaries) or previous surgeries due to Crohn's disease (adhesions in the lesser pelvis and changed anatomy in the abdominal cavity).

It is known that surgeries in the pelvic or abdominal regions may affect fertility. Women with a constructed pouch (a reservoir for stools attached to the anus and surgically constructed from a portion of the small intestine that replaces the removed rectum) have a two- to three-times reduced ability to get pregnant compared to the general population.

# Does medication affect conception and pregnancy?

**There is no evidence that the medications for IBD treatment themselves have an effect on the ability to get pregnant.**

In most cases, it is recommended to continue treatment, since this maintains the inactive phase of the disease. This is

crucial to reduce the potential for a relapse during pregnancy and ensure a healthy pregnancy and childbirth.

# Does IBD increase the risk of miscarriage?

Many studies have confirmed that the risk of miscarriage doubles if a female gets pregnant during an **active phase**. This is most probably due to **increased inflammation** that occurs with the release of several inflammatory transmitters which may harm the unborn baby and mother. Another rea-

son could be an **incomplete absorption** (malabsorption of **certain substances** that are important for a healthy pregnancy, such as minerals, proteins, and vitamins) due to IBD. The deficiency may lead to abnormalities in the early development of the unborn baby and, consequently, to miscarriages.

# What can I do to improve the course of pregnancy?

When planning pregnancy, it is of utmost importance that **both partners** take dietary and other good and bad habits into consideration. We know today that habits and tendencies towards certain habits may be partially inherited from the mother and father, which negatively affects the growth and development

of their child. Therefore, **healthy habits should be maintained: regular exercise, a varied and balanced diet, no smoking, consuming as little alcohol and caffeine as possible, avoiding stress, and giving up other unhealthy habits.** Special testing for certain diseases prior to pregnancy is not required.



It is recommended to exclude **anaemia** before getting pregnant and to check if the pregnant woman was vaccinated according to the programme or if she has had any of the diseases in the past.



## When to start taking food supplements prior to pregnancy?

If the diet is balanced, there is **no need for food supplements**, since a woman gets all the necessary nutrients with food.

This is not true in case of active IBD or a larger portion of the intestine was removed due to the disease, since the disease may cause malnutrition with the deprivation of proteins, iron, certain minerals, vitamins and other essential substances. In such cases, counselling prior to pregnancy should involve a nutritionist who will help create a diet plan.

Three months before conceiving, it is recommended that the woman starts taking **folic acid** which is then used during the

whole duration of pregnancy and breast-feeding according to the physician's instructions. Folic acid plays a key role in the healthy development of the baby, since it is involved in the synthesis of proteins, cell division, bone marrow function (where blood is made) and prevents abnormalities in the development of the cardiovascular system, and is crucial for the healthy development of the central nervous system of the baby.

In the case of **iron** deficiency (anaemia), iron supplementation is recommended until iron levels in the (future) mother are restored.

## Whom can I consult with if I plan to get pregnant?

First, contact your gynaecologist and gastroenterologist. If necessary – especially following major surgeries on the intestine or in the area of the musculature and skin of the pelvic floor (*perineum*) – your gynaecologist will refer you to a preconception counselling where they will explain the procedures and tests you are expected to undergo during pregnancy, what you should pay attention to, and what will happen

during the labour and postnatal period. If IBD worsens during pregnancy, your gynaecologist will refer you to the outpatient clinic for pathological pregnancy, where physicians specialising in healthcare of pregnant women, birthing mothers, and newborns (*perinatologists*), in cooperation with gastroenterologists, make sure your pregnancy and labour will be as safe as possible for you and your baby.

## Can IBD of the father affect the conception and development of a child?

Men with IBD in remission have comparable ability to conceive a child as men in the general population.

The ability of a man to conceive a child may be reduced during active IBD; however, it returns to normal when remission

is achieved. It may also be reduced following surgeries due to IBD.

There is no data on IBD in men increasing the occurrence of abnormalities in children.

## Can medications reduce the ability of conception and affect the development of the child?

Most IBD medications in men have no proven negative effect in their ability to conceive children. In certain exceptions, a specialist will inform you of precautions or adjust your ther-

apy. If you are worried or in doubt and you are planning a family, consult your gastroenterologist.



As with planning, effective control over the disease is crucial during pregnancy in women with IBD. Medications do not pose risks during pregnancy; however, active IBD does.

# Pregnancy

It is important, that pregnant women with IBD receive guidance and monitoring by a gastroenterologist, gynaecologist, and in more complicated cases, a surgeon. As with all pregnant women with IBD are advised to lead a healthy lifestyle, with regular exercise and a balanced diet.



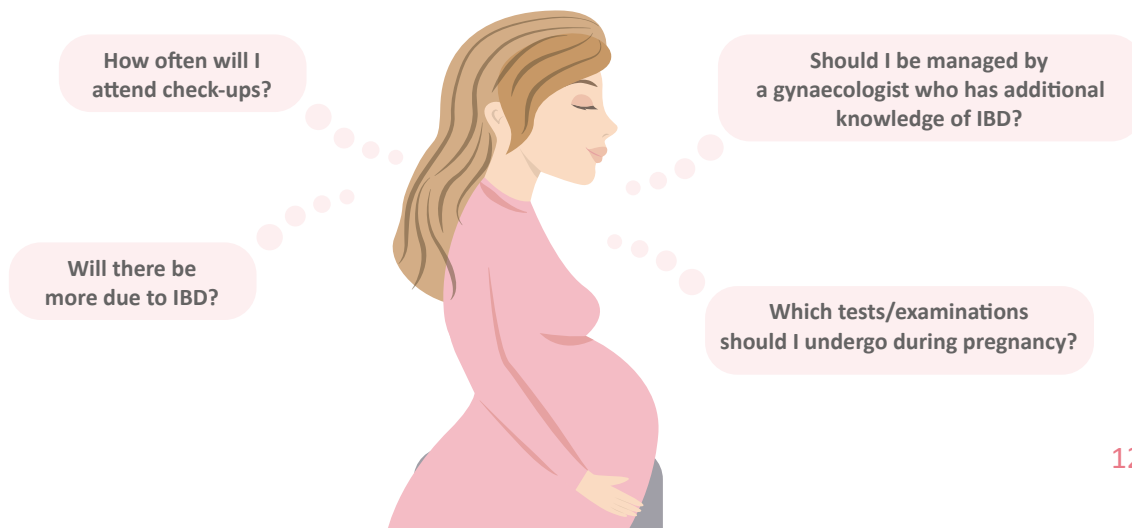
## Will my disease worsen when I get pregnant?

There **are no rules** when it comes to the course of the disease during pregnancy. Studies have confirmed that the possibility of a IBD relapse during pregnancy is comparable to non-pregnant women if IBD was inactive at the

time of conception. However, if the disease was active at the time of conception, its activity will also be increased during pregnancy. Therefore, a **remission** of IBD should be achieved **before conception**.

Some experts claim that women have fewer surgeries following childbirth and a longer interval between surgeries, which could even suggest an improvement of the disease.

## What about gynaecological examinations?





### IBD IN REMISSION

Simplified monitoring of the disease during pregnancy.

The pregnancy is comparable to other pregnancies.

**Regular check-ups with your gynaecologist are sufficient.**

The schedule of check-ups is the same for all pregnancies: a gynaecologist monitors the course of the pregnancy and the development of the baby; a pregnant woman may consult the gynaecologist also if there are any issues.

### ACTIVE IBD

**More frequent ultrasound examinations** (weekly if required) for monitoring the growth and development of the baby.

Management in a clinic for pathological pregnancy is recommended for: a pregnant women with relapsed IBD, pregnant women treated with biologic therapy, and when there is partial improvement in the disease.

Relapse requires proper and prompt treatment of IBD.

During pregnancy, IBD is usually monitored with tests and examinations that do not pose high risks, for example laboratory tests involving blood and stool. In most cases, these tests are sufficient for monitoring IBD activity.

## Are there any examinations I am not allowed to undertake during pregnancy?

**No.** There are no examinations that you are not allowed to undertake.

If your physician considers the examination justifiable, even endoscopic examinations of the intestine may be carried out. Imaging examinations usually include ultrasound of the ab-

domen that is not invasive and does not involve radiation. When necessary, also computer tomography (CT) of the abdomen, x-rays, or magnetic resonance imaging (MRI) may be carried out. Colonoscopy, CT, and MR have no harmful effects on the development of the baby.

## Do I have a higher risk of blood clots due to IBD?

Pregnancy itself increases the risk for blood clots (*thromboembolism*) by five-fold. However, an active IBD presents an even higher risk; therefore, it is recommended to **assess the risk for blood clots**. When the risk is high, a prophylaxis with medicines that help preventing blood clots is considered.

The pregnant woman should pay attention to the following **symptoms**: swelling, pain, and redness in the lower extremi-

ties may be indicative of a clot in the deep veins.

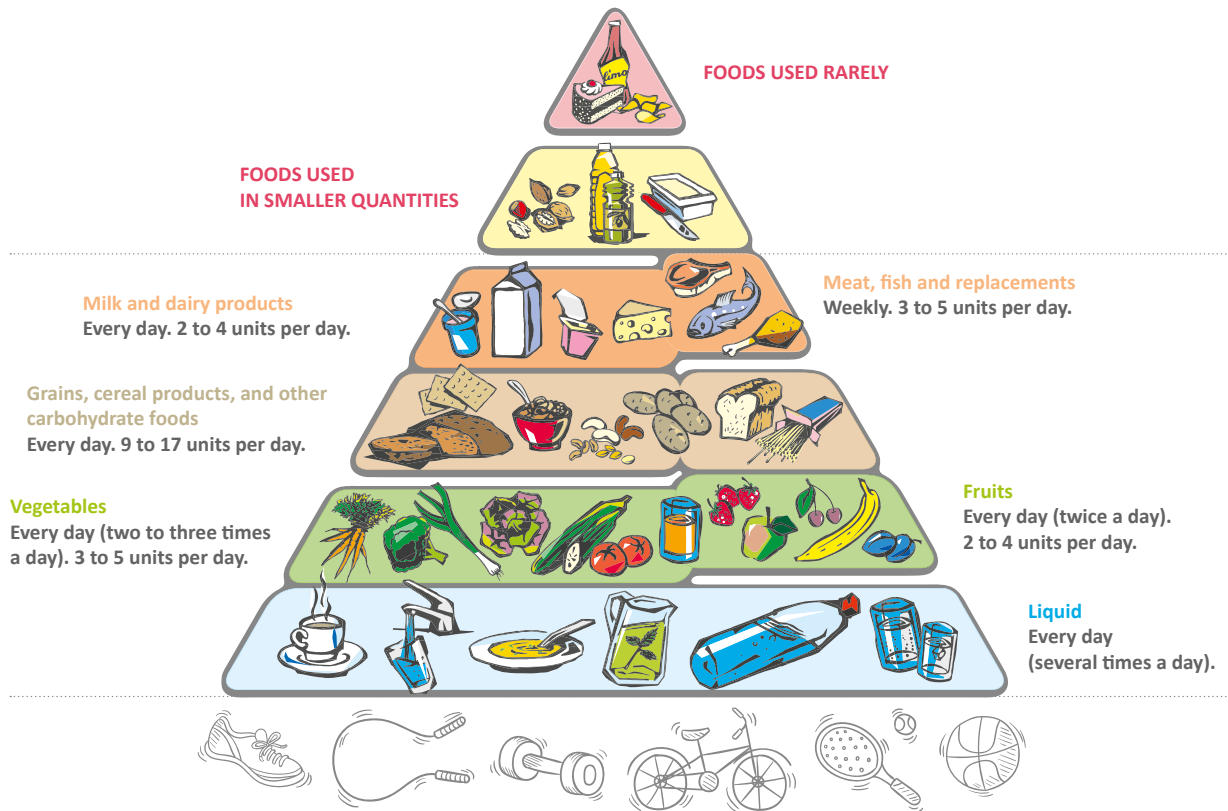
If this is not treated, the clot may dislodge and block a blood vessel in the lungs which leads to: breathing difficulties, loss of consciousness or vertigo, chest pain, cough and expectoration. This is a life-threatening condition; therefore, **medical care should be sought immediately** if these symptoms occur.

Proper diet is crucial for maintaining health during all phases of family planning: before pregnancy, during pregnancy, and during breast-feeding. Only a healthy and balanced diet ensures proper care for yourself and your baby. Reserves of nutrients for the growth and development of the baby should be produced three to four months prior to conception.

# Nutrition and food supplements

In addition to balanced meals, normal meal portions are recommended for the pregnant woman. It is a common misconception that a woman should eat “for two” during pregnancy. The food pyramid of the National Institute of Public Health may be used as a guidance for healthy nutrition.





**Maintain moderate physical activity** (e.g. fast walking, easy cycling on flat roads, slow swimming) for at least 150 minutes per week, e.g. 5-times a week for half an hour, or high-intensity physical activity (jogging, walking up the stairs, aerobics, tennis) for at least 75 minutes a week, e.g. 3-times a week for 25 minutes.

**IT IS RECOMMENDED TO PREPARE VARIED MEALS CONSISTING OF FOODS FROM ALL GROUPS, AND AT THE SAME TIME MAINTAIN A BALANCE IN THE MEALS IN TERMS OF NUTRIENTS AND ENERGY VALUE.**



# Which food supplements should be taken during pregnancy?

By following a balanced diet, a pregnant woman usually gets all the nutrients needed for a healthy pregnancy and baby development.

Folic acid is one of the most important substances to be taken while planning pregnancy, during pregnancy, and breast-feeding, since it helps with the proper development of the baby. Folates play an important role in the synthesis of DNA and amino acids, and in cell division. Their deficiency in the first trimester may cause defects in the development of the baby.

Deficiency in folic acid may cause recurrent miscarriages.



**Folic acid** is the only essential food supplement for every woman planning pregnancy.

Recommended daily dose:

- 400 µg prior to conception
- 4000 µg from conception to childbirth
- 400 µg after delivery, during breast-feeding

# What about magnesium?

In case of magnesium deficiency the World Health Organisation (*WHO*) recommends a dose of **300 mg magnesium per day**.

Acute deficiency may cause cramps in the calves, slight and mild cramps in the pregnant uterus, etc. In such cases, magnesium should be taken even when the problem has been resolved, in order to restore the levels in the body.

Magnesium use may temporarily cause **softer stools or diarrhoea**, which is **not dangerous** and usually resolves on its

own. The excess magnesium in the intestine binds water, which leads to the »dilution« of the bowel content. In such cases it is recommended to lower the magnesium dose.

Unlike other laxatives, magnesium does not cause direct irritation of the intestinal wall; therefore, if used as indicated, **does not lead to IBD exacerbation**.



# What about anaemia due to iron deficiency?

**Anaemia in pregnant women with IBD occurs with the same frequency as in other pregnant women.**

During every pregnancy, iron requirement is higher, since the pregnant woman has to produce enough *haemoglobin* (a protein that carries oxygen to the organs) for herself and her baby. For that reason, it is recommended to **ensure adequate iron levels prior to conception**, since this helps reduce the risk of anaemia during pregnancy.

Blood tests are periodically carried out during pregnancy and their frequency depends on your health status. It is important to detect a potential iron deficiency as soon as possible and ensure an adequate iron intake in the form of **proper diet or medi-**

**cines**, which are usually administered *intravenously* in pregnant women with IBD. This ensures that the baby and mother do not suffer from the consequences of iron deficiency.

Severe anaemia may cause serious complications in pregnancy (preterm labour, intrauterine growth restriction or even intrauterine foetal death), and major bleeding during and after the delivery. A newborn from an anaemic mother has lower iron reserves and, therefore, a higher risk of developing anaemia in the first year of life when the iron intake with food is low. Therefore, some children are given iron supplements.

You should pay particular attention to symptoms and signs of anaemia and consult your physician who will give you proper recommendations.



FATIGUE,  
REDUCED  
PHYSICAL FITNESS



HEAVY  
BREATHING AT  
EXERTION



PALE SKIN  
AND VISIBLE  
MUCOUS  
MEMBRANES



HEADACHE,  
DIZZINESS,  
FAINTING



PALPITATIONS



RINGING  
IN THE EARS



IRRITABILITY

## Do I need to stop taking medicines during pregnancy?

**No! This would be the biggest mistake that a woman can make. The risk is posed by the active disease and not the medicine.** In order to lower the risk of IBD relapse during pregnancy, a maintenance therapy prior to conception is recommended. Acute disease relapses are associated with a high risk of complications during pregnancy (miscarriage, preterm baby, low birth weight, etc.).

If you have any concerns regarding your therapy prior to conception, consult your gastroenterologist.



**NO**, This would be the biggest mistake that a woman can make. The risk is posed by the active disease and not the medicine.

# How is acute IBD relapse treated during pregnancy?

Acute IBD relapse during pregnancy may cause severe complications for the mother and the baby; therefore, adequate and prompt treatment is crucial. Treatment of

relapses during pregnancy is comparable with treatment of non-pregnant women.

## Can biological medicines cause bleeding during pregnancy?

Biological medicines **do not cause bleeding** on their own.

Their passage through the placenta up to week 20 is negligible, but it increases when approaching delivery. In the second half of the pregnancy and prior to delivery, the duration of treatment with biological medicines that will not endanger the mother and the baby is determined, together with a gastroenterologist and *perinatologist*.

Intestinal bleeding is the consequence of **IBD exacerbation** and presents a significant indication for intervention. In such cases, a prompt follow-up by the gastroenterologist is recommended who will try to alleviate the relapse with medications.



**PERINATOLOGIST** – a subspecialist gynaecologist with an in-depth knowledge and techniques in obstetrics, i.e. a gynaecologist specifically involved with prevention and treatment of complications during pregnancy and childbirth.

## What about the use of antibiotics and other medications during pregnancy?

Antibiotics that are safe for pregnancy are used. Treating infection during pregnancy is extremely important, since there is a high possibility of the infection spreading which may endanger the mother and the baby.

The prescribed antibiotic is always selected to enable as ef-

fective a treatment as possible, without any harmful effects on the baby.

The same applies for other medications. However, it is important to inform the treating physician of your pregnancy or suspected pregnancy.

## What about ostomy during pregnancy?

The function of ostomy during pregnancy is usually normal and does not cause issues other than those in non-pregnant women. Due to the activity of certain hormones during preg-

nancy, bowel movements slow down, which may be beneficial with regard to the frequency of emptying the bag.

# Childbirth

A method of delivery in women with IBD is determined by the gynaecologist after consulting with the gastroenterologist and, if necessary, a surgeon. Most women with IBD deliver vaginally. Patients with a more severe course of disease, worsening of the disease, or significantly active disease during the perinatal period are advised to have a caesarean section.

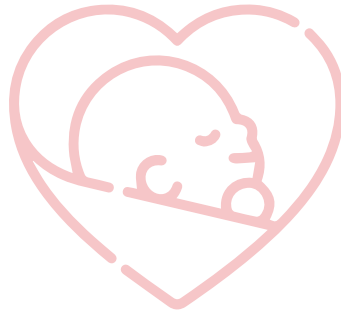
# Is it possible to deliver both vaginally and via a caesarean section?

**Yes.** The pregnant woman should discuss suitable delivery methods with the gynaecologist.

The incidence of planned caesarean sections is increasing, especially due to caesareans being performed following previous caesarean sections. In women with IBD, this incidence is a bit higher due to complications of IBD and surgical treatment. According to NPIS (National Perinatal Information System) data, 22.7% caesarean sections are planned in a healthy population and 27.1% in women with complications associated with IBD. The incidence of urgent caesarean sections

due to acute complications during active labour is the same as in a healthy population.

However, in certain cases, the progression of vaginal delivery may be comparable to other pregnant women – e.g. in women with ostomy. When urgent caesarean section is required, the location of the ostomy must be considered and the process adjusted accordingly.





## Does a caesarean section pose higher risk?

In women who underwent surgeries in the abdominal cavity due to IBD or any other diseases or injuries in the past, re-entry into the abdominal cavity may be difficult and prolongs entry into the uterus and access to the baby.

This should be considered when planning the delivery; therefore, the decision on performing a caesarean section

may be taken earlier than in pregnant women without prior abdominal surgeries.

When planning a caesarean section, a surgeon who is present during surgery should always be notified of the intended surgery.

## Does caesarean section create the risk of relapse?

No, the method of delivery has no effect on the risk. It is important to continue with the maintenance therapy after the delivery in order to prevent relapse. In approximately one

third of the women, relapse occurs within a year following delivery, which is comparable to women who have not given birth.

# Can childbirth affect ostomy, ileoanal pouch, or perianal fistula?

Vaginal delivery and the presence of active *perianal fistula* presents a higher risk for more extensive perineum injury during childbirth that cannot be prevented even with a surgical perineal incision (*episiotomy*). In case of inactive or surgically managed *fistulas*, the possibility of vaginal delivery depends on the extent of scars on the perineum and birth canal, and on the elasticity of scarred tissues.

In the second half of the pregnancy, the gynaecologist and pregnant woman discuss possible complications, and decide on the method of delivery. Vaginal delivery without complications does not cause new *perianal fistulas*, which are caused by uncontrolled perineal injuries and poor healing following surgical management.

In the presence of a *ileoanal pouch*, delivery with a planned caesarean section after week 38 is recommended, since experience with vaginal deliveries are insufficient.



**OSTOMY** – a surgically created opening that connects a hollow organ with the skin (e.g. connection between small intestine and skin – *ileostomy*, and connection between large intestine and skin – *colostomy*). It is used for defecation.

**ILEOANAL POUCH** – a reservoir for stools attached to the anus which replaces the removed rectum. It is surgically constructed from a portion of the small intestine.

**PERIANAL FISTULA** – abnormal tubular connection of the rectum and skin surrounding the anus.

## Am I more susceptible to inflammation and infection due to biological medications?

Yes, especially inflammation of the uterine mucous membrane (*endometritis*) and breast inflammation (*mastitis*) following delivery; often, worsening of chronic inflammation of sweat glands on the skin (*acne inversa* or *hidradenitis suppurativa*).

During pregnancy, the woman is tested for **streptococcus B**. If it is present, precautions are taken to prevent transmitting the bacteria to the newborn. This infection is common in all women and may cause complications in newborns due to early infection (known as *neonatal streptococcal sepsis*).

## Will the strain of vaginal delivery affect my bowel?

The strain of vaginal delivery is comparable to that of defecation (bowel movement) following constipation. Therefore, similar undesirable effects on the intestine may occur as in non-pregnant women (e.g. prolapse of the end portion of

the large intestine through the anus – *rectal prolapse*). Adequate guidance and management during vaginal delivery may successfully prevent majority of the undesirable effects.

## Will the labour make me feel even more tired?

The fatigue after vaginal delivery goes away in six to eight hours. After the perineal incision, the feeling of painful perineum may remain and may worsen when sitting. If a caesarean section is performed, the pain in the region of the abdominal wound and recovery are prolonged. Poor sleep quality due to frequent waking of the newborn and their

care also increases fatigue. Therefore, it is recommended that the birthing mother rest and sleep in the first 24 to 48 hours after the delivery. During this time, the nurses at the ward usually care for her and the baby. However, only few women take this advice, since they are too excited about a new family member.

## Is the use of enema prior to delivery suitable for me?

Women with IBD are not offered enemas – as is the case with some other women – however, they can decide for themselves. It should be noted that the privacy of the setting during delivery is always taken care of. If, during delivery, there is a bowel movement due to the disease, the midwife will

discretely take care of it and provide as hygienic an environment as possible for the newborn. After the delivery, the privacy of the mother is also maintained and, if possible, she is hospitalised in a room with a private bathroom.

# Breast-feeding and postnatal period (period after the delivery)

Lactation and breast-feeding have no significant effect on the IBD activity and do not present an increased risk of relapse. However, a relapse may be caused by the discontinuation of treatment, most often due to fear of possible harmful effects of medications being passed into the milk and to the baby. Your gynaecologist or gastroenterologist will surely inform you of rare exceptions when breast-feeding is discouraged.

## Can I breast-feed despite taking medicines?

**Yes**, since the passage of most IBD medicines into mother's milk is poor.

Breast-feeding is also not associated with an increased risk of

relapse and may even be protective against relapses.

Breast-feeding is discouraged only in rare cases, which will be pointed out by your gynaecologist.

## What should I pay attention to with my baby?

The effect of biological medicines on the baby's immunity is negligible. When taken as prescribed, the amount of medicines in the baby's circulation is too low to have an effect on the function of the baby's immune system.

As a general rule, it is recommended that **all** pregnant women are in contact only with **healthy individuals**; and even then only for a short time and not within the first 14 days when the family gets used to a new schedule and the bond between the mother and the baby is established. All newborns are usually more susceptible to infections due to their immature immune system which is just starting to recognise

germs that can cause disease in the environment. The function of the baby's immune system may be supported with the mother's breast-feeding, which help to protect babies from serious illness by receiving antibodies in the breast milk.

It is recommended that the baby be vaccinated according to the vaccination programme for general population. The exception is live vaccines that are given between 6 and 12 months of age, if the baby's mother received biological medicines during pregnancy. Examples of this are rotavirus and tuberculosis vaccination.

# Will my child get IBD?

Children of parents with IBD have a **higher risk** for the development of this disease during their lives, since they are affected by genetic factors. In addition to this, several other unpredictable factors also contribute to the development of IBD.

Statistics show that approximately 5 to 20% of patients have a family member with a IBD.

The risk for a sibling of a patient with Crohn's disease in developing the disease is 2 to 3%, and for a sibling of a patient of ulcerative colitis it is 0.5 to 1%. If both parents have IBD, the probability of their child developing the disease during their lifetime is 30%.



## Should my child undergo additional examinations?

Preventive follow-ups with a paediatric gastroenterologist **are not necessary**. However, we should be aware of the increased risk for the development of IBD, and perform examinations to confirm or exclude IBD if symptoms (e.g. bloody

diarrhoea, abdominal pain, weight loss) or blood test abnormalities (e.g. increased blood CRP concentration, anaemia) occur.

## Can my IBD affect the health of my child?

Since, with medicines we are able to prevent the disease from exacerbating during pregnancy, children born to women with IBD are fully **comparable to children born to women in the general population** with regard to weight, length,

head circumference, and number of congenital defects or genetic diseases. IBD in remission or taking prescribed medications during pregnancy does not increase the risk of congenital defects in newborns in any case.



## Can my IBD affect the development of my child?

If the pregnancy is normal and the child is born on the due date, normal physical and mental development of the child is expected. Children of parents with IBD achieve comparable developmental milestones as their peers with parents who don't have the disease.

An increased risk of abnormal development of motoric and mental abilities may be caused by a possible preterm delivery. All children born prior to week 37 are at risk, especially those born before week 32.

## Can my IBD affect the development of other diseases in my child?

**It might.** The child inherits a genetic code in which several genes for IBD are common to other immune-mediated diseases, which points to a likely increase in the incidence of

these diseases in patients with IBD. An example of such a disease is rheumatoid *arthritis*, which is more common in patients with IBD according to studies.

## Can IBD affect my sexual intimacy?

Sexual function and activity in patients with IBD generally do not differ from that in the general population. Decreased sexual desire may be the consequence of an active disease and its course, since they often lead to avoidance of social contact and poor social life. Psychological factors, bad mood,

changed perception of appearance and body, constant fatigue, partner's lack of understanding, and frequent hospitalisations may additionally hinder normal sexual activity. These problems often require a consultation with a psychologist or gynaecologist – specialist for sexual medicine.

## Do I have a higher risk of cervical cancer due to IBD?

Women with IBD do not have higher incidence of precancerous or cancerous lesions on the cervix.

## Should I store stem cells?

**Storing stem cells** from the umbilical cord blood in patients with IBD on biological medicines **does not differ from that in other women.**

At the collection, it must be documented which medication the mother used and when the last dose was taken, as this determines the concentration of medication in umbilical cord blood.

There is no consensus on the relevance of the collection, especially on the storage of stem cells from umbilical cord blood in case of possible autoimmune disease in newborn.

Based on the current understanding in medicine, the use of one's own stem cells (*autologous*) does not make sense, since stem cells also carry the code for the autoimmune disease affecting the child or adult.

## Is there anything special about taking oral contraceptives?

Prevention of pregnancy by means of oral contraceptives **does not differ from that in general population.**

However, **remissions** reduce the efficacy of oral contraceptives due to the disturbed uptake of hormones from the digestive tract. Therefore, the **insertion of intrauterine system contraception (IUS)** into the uterine cavity is most often recommended as a reliable contraception. A hormone

preventing pregnancy is thus released locally and the systemic effect of hormones on the user's body that could worsen IBD is avoided. The use of a copper intrauterine device is not advised, since it can release substances promoting inflammation and, consequently, exacerbate the condition. The contraception is withdrawn three months prior to the planned pregnancy, following the preconception counselling and examination.

# Glossary

**Glossary authors:** Tina Kurent dr. med., specialistka gastroenterologije and prof. dr. Ivan Ferkolj, dr. med, specialist interne medicine in gastroenterologije

- **ABSCESS** – is a local collection of pus caused by bacterial infection. In patients with Crohn's disease, abscesses may form around the rectum, and less commonly in the abdominal cavity adjacent to the intestinal flexures.
- **ANAL FISSURE** – due to pressure during defecation, the mucous membranes or skin of the anal canal may tear and create a *fi ssure* that is very painful. Bleeding may also occur.
- **ANAL SPHINCTER** – circular muscle wrapped around the anal canal that controls its opening and closing – i.e. defecation.
- **ANASTOMOSIS** – connection/fusion of two portions of the intestines after surgically removing the affected portion.
- **ANUS** – the end portion of the intestine closed by the muscle called *anal sphincter*.
- **ASCENDING COLON** – a portion of the large intestine which connects the cecum and transverse colon on the right side of the abdomen. See figure.
- **ASUC** – Acute Severe Ulcerative Colitis is an abbreviation for a sudden (*acute*) severe relapse of ulcerative colitis. Such patients require hospitalisation and inpatient treatment.
- **BAUHIN'S VALVE** – see explanation for ileocecal valve.
- **BIOLOGICAL MEDICATION** – a medication containing the active ingredient manufactured or derived from live cells (human, animal, microbial). In IBD, it is used for targeted reduction of inflammation.
- **BIOPSY** – a sample collection to be examined under the microscope or intended for any microbiological analyses.
- **CAPSULE ENDOSCOPY** – an examination of the small intestine by using a capsule swallowed by the patient. The capsule transfers the images to the disc that the patient carries on the belt.
- **CECUM** – the first part of the large intestine located in the lower right abdomen. The appendix and small intestine open into it.
- **CHOLESTYRAMINE** – a substance that binds bile acids and may also be used for treatment of diarrhoea in patients in whom the end portion of the small intestine and the first portion of the large intestine have been removed. Due to the missing portion of the intestines, the body cannot absorb bile acids and causes diarrhoea due to accumulation in the large intestine.

- **CMV** – an abbreviation for cytomegalovirus. Sometimes, this virus is detected in patients with an exacerbated inflammation of the large intestine. It is not clear if CMV infection worsens inflammation of the large intestine or if the virus multiplies due to the current inflammation.
- **COLECTOMY** – surgical removal of the large intestine. Total colectomy is used for the removal of the whole large intestine including the *rectum*.
- **COLITIS** – inflammation of the large intestine.
- **COLON** – another term for the large intestine.
- **COLOILEOSCOPY** – an examination of the large intestine and the end portion of the small intestine or *terminal ileum* with a device called *endoscope*.
- **COLONOSCOPY** – an examination of the large intestine with a device called *endoscope*.
- **CORTICOSTEROIDS** – hormones produced in the adrenal cortex. They are used for the treatment of IBD relapse, since large concentrations rapidly and effectively alleviate inflammation.
- **CROHN'S DISEASE** – a type of chronic inflammatory disease that affects sections of the digestive tract, from the mouth to the anus. The most commonly affected part of the digestive tract is where the small and large intestine are in contact, also called the *ileocecal region*. The affected portions of the bowel include swollen and red tissue, and small or large lesions with minor bleeding. Inflammation may extend deep into the tissue and lead to complications, such as scars causing the narrowing of the intestine, *fistulas* and *abscesses*.
- **CRP** – C-reactive protein is present in the blood and is produced in the liver as a response to inflammation or infection in the body. Blood CRP concentrations are increased in immune-mediated diseases, such as IBD.
- **CT** – Computed Tomography. This is a type of imaging medical examination using x-rays to create a three-dimensional image of the inside of the body enabling a detailed examination of organs, blood vessels, and other structures.
- **DESCENDING COLON** – a descending portion of the bowel that connects the transverse colon and sigmoid colon on the left side of the abdomen.
- **DIARRHOEA** – is defecation with watery or very soft stool more than three times a day.
- **DILATION** – widening. In patients with IBD, the portion of the narrowed intestine may be dilated with a device intended for observation of the inside of the intestine, also called *endoscope*.
- **DISTAL** – a term describing a more distant part from the torso/core. In the digestive tract, it describes the section that is further or lower with regard to the direction of contraction (*peristalsis*).
- **DIVERTICULUM** – a small bulge or pocket on the intestinal wall due to the injury in the muscle layer. With age, their number increases, but they usually do not cause any issues. Some of them can progress to inflammation called *diverticulitis* or bleeding from diverticulum.

- **DUODENUM** – the first portion of the small intestine beginning at the end of the stomach and continuing into the *jejunum*.
- **DYSPLASIA** – abnormal shape, size, growth, or structure of cells that may present precancerous or *premalignant* lesion.
- **ENDOSCOPE** – a device for examining the inside of the body. When examining the digestive tract, a gastroscop is used for the upper digestive tract (oesophagus, stomach, duodenum), *colonoscopy* for the lower digestive tract (end of the small intestine and the large intestine), and *capsule endoscopy* for the whole small intestine.
- **ENDOSCOPIST** – a physician who examines the inside of the body with a device called *endoscope*.
- **ENEMA** – fluid injected into the bowel. An example is *hydrocortisone* enema that alleviates inflammation in the rectum and sigmoid colon.
- **ENTERITIS** – inflammation of the small intestine.
- **ENTEROPATHIC ARTHRITIS** – chronic inflammation of one or more joints associated with IBD. It may be classified as inflammation of joints in extremities called *peripheral arthritis* that usually accompanies active intestinal inflammation, and inflammation of joints of the lower back and pelvis called *axial spondyloarthritis*.
- **ERYTHROCYTE** – red blood cell.
- **EXTRAINTESTINAL SIGNS** – in addition to the inflammation of the bowel, other organs are also affected in IBD. It most commonly affects the skin and joints and, rarely, eyes, liver, and lungs.
- **FEBRILE** – with fever.
- **FERRITIN** – a protein that contains iron and is one of the main forms of storing iron in the cells. Low concentration is indicative of iron deficiency. Ferritin concentration is elevated in the presence of inflammation and excess iron (e.g. *haemochromatosis*).
- **FISTULA** – an abnormal tube-like passage between two hollow organs or a hollow organ and skin surface. Fistulas may be a complication of Crohn's disease. The most common is *perianal fistula* that connects the rectum and skin surrounding the anus. Fistulas may also connect two flexures of the small intestine (*enteroenteric fistula*), small and large intestine (*enterocolic fistula*), intestine and vagina (*enterovaginal fistula*), intestine and bladder (*enterovesical fistula*) or intestine and skin surface (*enterocutaneous fistula*).
- **FULMINANT COLITIS** – rapid, severe relapse of inflammation in the large intestine that may lead to the widening of the large intestine called *toxic megacolon*.
- **GASTROENTEROLOGY** – a branch of medicine involved with diagnosing and treating digestive diseases.
- **HAEMOGLOBIN** – a protein in red blood cells or *erythrocytes*, that transfers oxygen to the tissues.



- **HAEMORRHOIDS** – abnormally enlarged veins in the anus. They are also called piles.
- **HEMATOCHEZIA** – passing light red stools which is usually indicative of bleeding in the lower digestive tract.
- **HEPATIC FLEXURE** – a curve of the large intestine under the liver, in the top right abdomen, that connects the ascending colon (*ascendens*) and transverse colon (*transversum*).
- **HISTOPATHOLOGY REPORT** – results of a tissue examination under the microscope.
- **IBD** – an abbreviation for chronic inflammatory bowel disease.
- **ILEUM** – the end portion of the small intestine that ends with a valve between the small and large intestine (*ileocelecal valve*), which then opens into the first portion of the large intestine (*cecum*).
- **ILEITIS** – inflammation of the lower portion of the small intestine.
- **ILEOCECAL REGION** – a contact point between the small and large intestine.
- **ILEOCECAL RESECTION** – surgical removal of the end portion of the small intestine or *terminal ileum* and the first part of the large intestine or *cecum*. The surgeon reconnects the remaining parts of the small and large intestine which is called *ileocolic anastomosis*.
- **ILEOCECAL VALVE** – a valve between the small and large intestine that enables the passage of bowel content in one direction only – from the small to the large intestine. It is also called *Bauhin's valve*.
- **ILEUS** – an intestinal obstruction that blocks and widens flexures above it. A patient with ileus suffers from abdominal pain, vomiting, constipation, or flatulence.
- **INTESTINAL ADHESION** – adhesion that develops during tissue regeneration following inflammation or surgery that connects intestinal flexures and organs in the abdomen. Their pressure may disrupt normal stool excretion through the intestines and thereby cause an obstruction or *ileus*.
- **IMMUNOCOMPROMISED PATIENT** – a patient whose body's ability to defend itself against foreign bodies (immune system) is weakened due to a disease affecting the immune system or due to medications.
- **IMMUNOMODULATORY MEDICATIONS** – medications that modify the activity of the immune system and are used for treatment of cancers, *infections* or other diseases. IBD is treated with *immunosuppressive* medications which weaken the immune response and, therefore, reduce inflammation.
- **INDETERMINATE COLITIS** – inflammation of the large bowel where examinations cannot confirm ulcerative colitis or Crohn's disease.

- **INCONTINENCE** – inability to hold back stool or urine.
- **INFLAMMATORY MARKERS** – biological markers in the blood which may help detect active inflammation in the body (e.g. calprotectin, C-reactive protein (CRP), sedimentation rate (SR), ferritin).
- **IPAA** – abbreviation for *ileal pouch–anal anastomosis*. A surgical technique for removing the entire large intestine and rectum and creating an inner pouch out of the small intestine, which is then sutured to the anus, enabling natural defecation.
- **JEJUNUM** – a portion of the small intestine between the *duodenum* and *ileum*.
- **LEUKOCYTES** – white blood cells that represent immune cells and are involved in defending the body against infections.
- **LIENAL FLEXURE** – *splenic curve* of the large intestine in the upper left abdomen where the transverse colon or *transverzum* traverses into the descending colon or *descendens*.
- **MICROBIOME** – a population of bacteria and other microorganisms. This term is usually used for the intestinal microbiome.
- **MR ENTEROGRAPHY** – imaging of the intestine with magnetic resonance (MR). Prior to this examination, the patient must drink a prepared liquid that sufficiently fills the intestine and enables imaging.
- **MUCOUS MEMBRANE** – the innermost layer of the intestinal wall that may be visualised during endoscopy.
- **OEDEMA** – a swelling – caused by fluid accumulation in the tissue that is the consequence of inflammation.
- **OSTOMY** – a surgically created opening that connects a hollow organ with the skin (e.g. connection between small intestine and skin – *ileostomy*, and connection between large intestine and skin – *colostomy*). It is used for defecation.
- **PANCOLITIS** – inflammation of the whole large intestine.
- **PARENTERAL NUTRITION** – food given through the vein.
- **PATHOGENIC ORGANISM** – a disease-causing organism (e.g. bacterium or virus).
- **PERFORATION** – perforation of the intestine causes a spillage of its content into the sterile abdominal cavity causing severe inflammation and usually requiring surgical treatment.
- **PERIANAL** – includes regions surrounding the *anus*.
- **PERISTALSIS** – movement of the digestive tract that enables the passage of a food bite, also called *bolus* from the first portion of the oesophagus to the end of the large intestine.
- **PLATELET** – disc-shaped blood cell that plays an important role in blood clotting.



- **POLYP** – a bulge of the mucous membrane that protrudes into the intestinal lumen. Some intestinal polyps pose a risk of developing colon cancer; therefore, they are removed during endoscopic examination. Pseudopolyps are common in IBD and are caused by chronic inflammation, and do not pose a risk of developing cancer; therefore, they do not have to be removed.
- **POUCH** – a reservoir for stools attached to the anus which replaces the removed rectum. It is surgically constructed from a portion of the small intestine.
- **POUCHITIS** – inflammation of the *pouch* – surgically created reservoir for stools.
- **PRESTENOTIC DILATION** – a widened portion of the intestine that is caused by the narrowing next to it.
- **PROXIMALLY** – a portion of the digestive tract that is higher with regard to the path of rhythmic contraction (*peristalsis*).
- **PROCTITIS** – inflammation of the rectum.
- **PROCTOLOGIST** – a surgeon specialised in the management of patients with rectal diseases.
- **PROCTOCOLECTOMY** – also called *total colectomy*. It is a surgical removal of the large intestine and rectum.
- **PYODERMA GANGRENOSUM** – ulcer-like lesions on the skin that may occur in patients with IBD.
- **RECTOSIGMOIDITIS** – also called *proctosigmoiditis*. Inflammation of the rectum and sigmoid colon or *sigma*.
- **RECTUM** – The end portion of the large intestine. Connects the sigmoid colon and the anus.
- **RELAPSE** – recurrence of the disease.
- **REMISSION** – resting phase of the disease achieved spontaneously or with treatment. Clinical remission means the absence of symptoms, biochemical remission the absence of laboratory signs of active IBD, and endoscopic remission the absence of inflammation in the mucous membrane during endoscopic examination of the bowel. If all the above criteria are met, this is defined as deep remission.
- **RESECTION** – surgical removal of a portion of an organ.
- **SIGMOID COLON** – a part of the large intestine in the lower left abdomen that connects the descending colon or *descendens* and the *rectum*.
- **SR** – Sedimentation Rate of red blood cells (*erythrocytes*) or the rate of spontaneous sedimentation of red blood cells. This method helps determine if there is inflammation in the body, as its value usually increases when the inflammation is present.
- **STENOSIS** – also called a narrowing or *stricture* which is caused by scarring, swelling or abnormal growth of the tissue into the lumen.



- **SUBCUTANEOUS** – this term is derived from Latin and means *under the skin*. Example: subcutaneous application of medications means application under the skin. The abbreviation used for this term is *SC*.
- **TERMINAL ILEUM** – the end portion of the small intestine that passes into the large intestine. Absorption of vitamin B12 and bile acids takes place there. This is the most common location of inflammation in Crohn's disease.
- **TOXIC MEGACOLON** – severely enlarged large intestine due to severe inflammation. This almost always requires surgery due to the risk of intestinal perforation.
- **TRANSVERSE COLON** – horizontal part of the large intestine that connects the ascending colon (*ascendens*) and descending colon (*descendens*).
- **TUMOUR** – abnormal tissue. This may be non-cancerous (called *benign*) or cancerous (called *malignant*).
- **ULCERATIVE COLITIS** – a type of chronic inflammatory bowel disease where the inflammation is more superficial, and which only affects the large intestine. Inflammation begins in the rectum and continuously spreads to a certain level which represent the border between affected and healthy intestinal mucous membrane.
- **ULCER** – a lesion, superficial tissue injury.

## Notes





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