

Crohn's Disease

How can I monitor my progress?

Your doctor will want to monitor your progress with follow-up appointments from time to time.

In general, here are some things you can do on your own:

- See your doctor regularly, even if you are feeling well.
- Discuss any concerns you have with your doctor when you visit.
- Report any changes in symptoms between visits. Try tracking your symptoms with the symptom self-assessment below.
- Help keep your Crohn's disease under control by taking your medications, even if you're feeling well. If you want to change your treatment, discuss this with your doctor before doing so on your own.
- Review the medications you are taking with your doctor. Be sure to check with him or her before taking any over-the-counter medicines (eg, NSAIDs), herbal remedies or dietary supplements, as these may affect how well your medicine works or may affect your symptoms.
- Exercise regularly and eat a healthy diet.

In between doctor visits, it is important that you follow your treatment plan and know what to do should a problem arise.

If you have any of these problems, contact your doctor as soon as possible:

- Blood in your stool
- Change in bowel habits that last for more than 10 days
- Severe abdominal cramps or pain
- Severe diarrhoea or bloody diarrhoea
- Weight loss with no known reason
- Unexplained fever lasting more than 3–4 days
- Constant fatigue
- Loss of appetite
- Nausea or vomiting for unknown reasons.

Other considerations

If you have mild disease, don't worry about the section on stoma care – you will have to have had surgery to have a stoma.

- **Stoma care:** If you need to have a stoma, perhaps after an ileostomy, the bag (or pouch) must be emptied several times a day. It can, however, be hidden with clothing and is not usually noticeable. Some people worry that there will be odour from the stoma, but this is not usually a problem. Your doctor or nurse can provide guidance on appropriate stoma care, and direct you to support groups run by other people who also have stomas to help answer your questions or address your concerns.
- **Support groups:** Joining a support group can help you connect with other people in your area for education, assistance and guidance. Many people say that meeting others with similar medical conditions can be very helpful, as well as fun.
- **Diary:** In addition to the checklist provided in this guide, you may find it helpful to keep a diary of your symptoms over the period of a month. An example is provided in [Living with IBD/ Achieving more with IBD](#).
- **Bone mineral loss:** Ulcerative colitis has been associated with an increased risk of bone mineral loss and hip fracture, possibly due to factors such as the use of corticosteroids, avoidance of dairy foods, poor absorption of nutrients and the inflammatory process itself. Your doctor may suggest that you have your bone density checked regularly with a scanning

machine called a DEXA. If bone density is low, treatment may be needed. Additionally, you can take steps to prevent bone loss, including:

- Regular weight-bearing exercise such as brisk walking, jogging or aerobics.
- Avoid smoking which can harm the bones.
- Get adequate amounts of calcium and vitamin D, and also possibly vitamin K.
- Consider maintenance treatment to prevent ongoing inflammation.

If you have mild disease, don't worry about the section on stoma care – you will have to have had surgery to have a stoma.

Self-assessment

If you're like most people, it's easy to forget the details around your symptoms, especially when you are sitting with your physician in the consultation. You may find it helpful to fill in this symptom tracking worksheet before you go, so that you are prepared to answer your doctor's questions more accurately in the consultation. Remember, it is important to be truthful: your doctor needs this information to make the best decisions possible about your care.

1. Overall, how have you felt?

Generally well / Slightly worse than usual / Bad / Very Bad / Terrible

2. Have you missed work/ sports/ other activities? Yes / No

How many days in the last week?

How often has your illness kept you from going out with friends or family?

Have you had to spend any days in bed? If yes, how many?

When were you last unwell from your Crohn's disease or ulcerative colitis?

3. Symptoms - have you had any of these problems?

Loss of appetite **Yes / No**

Nausea **Yes / No**

Vomiting **Yes / No**

Fatigue **Yes / No**

Mouth ulcers **Yes / No**

Fever **Yes / No**

Joint pain or swelling **Yes / No**

Weight loss **Yes / No**

Depression or sadness **Yes / No**

4. Abdominal pain?

None / Mild / Moderate / Severe

If you had abdominal pain, how often?

Where was the pain?

Tips to try for cramping/ gas/ wind:

- It may help to adjust your diet and avoid 'gassy' foods such as baked beans, onions, cabbage and whole grains. Also try cutting out hot spicy food and fruit or vegetable skins. Consider any food intolerances such as milk or wheat. It may also be helpful to restrict your intake of certain high-fibre foods such as nuts, seeds, corn, popcorn and various Chinese vegetables. However, it is important to eat a balanced diet. If cutting out a food doesn't help, then reinstate it later.
- Try eating smaller meals (5–6) throughout the day rather than fewer (2–3) larger meals.
- Try to take a 30-minute break after eating to digest your food.

5. Stools

Number per day

Formed **Yes / No**

Loose **Yes / No**

Any blood? **Yes / No**

Do you have to use the toilet at night? **Yes / No**

Do you feel the need to go but can't? **Yes / No**

Have you had any accidents? **Yes / No**

Tips to try for managing diarrhoea:

- Try avoiding high fibre foods or spicy, hot or refrigerated foods, unripe or dried fruit or fried food. Drink decaffeinated drinks.
- Natural remedies such as chicken and rice soup, carrot soup, zinc and vitamin A supplements may also help.
- Your doctor may recommend the use of anti-diarrhoeal drugs (eg, loperamide), antispasmodic drugs, bulking agents or bile salt drugs to help slow the movement of bowel contents. If you are having a flare-up, however, check with your doctor before taking any medicines, even those available over-the-counter.
- Remember to drink plenty of fluids to help avoid dehydration.

6. Medications

What medicine(s) are you taking?

How often do you take your medicine?

Have they helped?

Any side effects?

How often do you miss a dose?

How satisfied are you with the relief of symptoms?

Are you taking any over-the-counter medicines, dietary supplements, herbal remedies or complementary medicines?