SYMPTOMS OUTSIDE THE BOWEL

Inflammatory Bowel Disease (IBD) can sometimes affect other areas outside the digestive system both during and between flare-ups such as:

- Joint pain and swelling (arthritis)
- Swelling in the eyes
- Mouth ulcers
- Skin rashes
- Fatigue
- Mental health problems

You can read more about how Crohn’s and Colitis affect other parts of the body in the Crohn’s & Colitis Companion.

SIDES EFFECTS

All medicines have a small risk of side effects. If you get any of these side effects or if you have any other side effects you are worried about while taking your medicine, contact your IBD Team or your GP as soon as possible. If it is an emergency call NHS 24 on 111 or call 999:

- Chest pain or rapid heartbeat
- A sore throat, unexplained bleeding, bruising or skin rashes
- Nausea, vomiting, stomach pain, jaundice or dark urine
- New or sudden pain in your abdomen that is different to your normal symptoms

Other side effects might include:

- Signs of an allergic reaction: hives (itchy rash on the skin), swelling of the face, lips, tongue or throat
- You feel depressed, high, or your moods go up and down. You feel confused, irritable, anxious, have suicidal thoughts or difficulties sleeping

More information can be found in your medicine packet leaflet and online at: crohnsandcolitis.org.uk/treatments

For help and advice:

- Crohn’s & Colitis UK Helpline on 0300 222 5700
- Call your IBD Team
- Call NHS 24 on 111
- Contact your GP
- Call NHS 24 on 111 when your GP surgery is closed
- Call the Crohn’s & Colitis UK Helpline on 0300 222 5700
- Visit nhsinform.scot/crohnsandcolitis.org.uk
- Email helpline@crohnsandcolitis.org.uk

This card was inspired by the work of Squires, Boal and Lamont (Implementing a self-management strategy in inflammatory bowel disease (IBD): patient perceptions, clinical outcomes and the impact on service, 2017) and was co-produced by Crohn’s & Colitis UK, the Scottish Government, patients and healthcare professionals.
Do you have any of these signs of a flare-up?

- Going to the toilet more than 5 times in 24 hours - or more than is normal for you.
- Loose stools or diarrhoea with any blood/mucus for more than 3 days.
- Abdominal pain.
- Just generally feeling worse, especially if you have a fever.

If you answer yes to any of these questions, please contact your IBD Team, your GP or NHS 24.

- Blood tests – full blood count, liver function tests, urea and electrolytes, albumin and CRP.
- Stool samples – one to check for bacteria/parasites, and ask if your GP can do either a test called faecal calprotectin or one called FIT, to check for inflammation. Call your IBD Team if your GP can’t test you for this.

These tests are useful to help decide on the best treatment.

If you have Ulcerative Colitis and are experiencing a flare-up, you can sometimes change your medication dose without consulting your doctor, while waiting for test results (though you should still inform them of any changes you make to decide).

- If you are taking 5-ASA's, it is safe to double your daily dose for 6 weeks:
  - Salofalk: from 1.5g to 3g per day
  - Asacol: from 2.4g to 4.8g per day
  - Mezavant: from 2.4g to 4.8g per day
  - Pentasa: from 2g to 4g per day
  - Octasa: from 2.4g to 4.8g per day

- If you have Ulcerative Colitis and are experiencing a flare-up, you can sometimes change your medication dose without consulting your doctor, while waiting for test results (though you should still inform them of any changes you make to decide).

5-ASA's

If you have Ulcerative Colitis, you might be prescribed:

- Salofalk: 1.5g - 2g per day
- Asacol: 2.4g - 4.8g per day
- Mezavant: 2.4g - 4.8g per day
- Pentasa: 2g - 4g per day
- Octasa: 2.4g - 4.8g per day

- Suppositories or enemas

If you have a supply of these at home, start these as well as increasing your 5-ASA tablets.

For more information about 5-ASA's, download the Crohn’s & Colitis UK leaflet crohnsandcolitis.org.uk/aminosalicylates

- Other medication

There are other types of medication for Crohn’s or Colitis that you are unable to stop or start without talking to your doctor. These are:

- Steroid tablets

Usually prednisolone is taken:

- starting with 40mg per day for one week
- reducing by 5mg per week for 8 weeks, 25mg tablets in total

Please tell your IBD team if your GP prescribes steroids.

If steroids work for you, your symptoms should improve within a few days.

You should NOT start taking steroid tablets without discussing with your IBD Team, and you should NOT stop steroids suddenly. They should be reduced gradually over a few weeks.

You might be prescribed:

- Azathioprine
- 6-Mercaptopurine
- Methotrexate

BIOLOGICS AND OTHER MEDICATIONS

If you are on immunosuppressants or biologics and you have an infection (e.g. flu, chest infection, skin infection), ask your IBD Team or GP for advice.

IMMUNOSUPPRESSANTS

You should NOT increase, decrease or stop these medicines without discussing it with your IBD Team.

You might be prescribed:

- Adalimumab
- Golimumab
- Vedolizumab

If you are an immunosuppressant user and a non-user (e.g. flu, chest infection, skin infection), ask your IBD Team or GP for advice.