Coronavirus (COVID-19) – Important advice for people with Inflammatory Bowel Disease (IBD)

This leaflet provides you and your family with information about how coronavirus (COVID-19) might affect you if you have IBD, including Crohn’s Disease, Ulcerative Colitis, IBD Unclassified or if you have Microscopic Colitis.

The most common symptoms of COVID-19 are a new continuous cough, loss of sense of smell or taste and/or a fever/high temperature (37.8°C or greater).

A new continuous cough is where you:

- have a new cough that’s lasted for an hour
- have had 3 or more episodes of coughing in 24 hours
- are coughing more than usual

A high temperature is feeling hot to the touch on your chest or back (you don’t need to measure your temperature). You may feel warm, cold or shivery.

Some people will have more serious symptoms, including pneumonia or difficulty breathing, which might require admission to hospital.

Your safety is our priority and we aim to minimise disruption to essential services. The NHS will continue to provide treatment for IBD, and emergency and urgent care for all patients. With that in mind we have listed some important information below. This includes answers to questions you may have and directions to services that can offer advice and support.

Some groups of people are considered to be clinically at high risk of severe illness from coronavirus (COVID-19). If you are in this group you will have received a letter from NHS Scotland or will have been contacted by your doctor. If you are in this group you should currently be following shielding measures:

https://www.gov.scot/publications/covid-shielding/pages/overview/

If you have IBD AND have been asked to shield you will find guidance for your situation elsewhere on this webpage https://www.gov.scot/publications/coronavirus-covid-19-tailored-advice-for-those-who-live-with-specific-medical-conditions/

What should I know about coronavirus (COVID-19) and IBD?

Some people with IBD have a higher risk of becoming ill if they have coronavirus (COVID-19) because their immune system is weakened. If this applies to you, you will be contacted directly by the NHS with advice that you should stay at home at all times and avoid all face-to-face contact until told otherwise. It is possible this advice will change as more information is available and, if so, you will be contacted again.

The British Society of Gastroenterologists has further information at https://www.bsg.org.uk/people/patients/.

Where can I get support?

If you have concerns related to your condition or your treatment your first point of contact should be your hospital IBD team.


For general information and any concerns about coronavirus (COVID-19) you can call 0800 028 2816 (COVID-19 helpline).

If you are the parent or carer of a child or young person with this condition you will be particularly anxious about what you should and can do to help and protect them at this time. Alongside the clinical advice provided in this leaflet there is further advice available on Parent Club on how to support your child at this difficult time. https://www.parentclub.scot/topics/health/coronavirus.

Crohns and Colitis UK have also produced a useful fact sheet, which can be viewed here: https://www.crohnsandcolitis.org.uk/news/coronavirus-covid-19-advice and a useful decision tree: https://www.crohnsandcolitis.org.uk/decision-tree.

For other non-emergency and non COVID-19 related health concerns, your GP or calling 111 should still be your first point of contact. At present they are likely to assess you over the telephone or via video link rather than see you in person to reduce the risk of infection from COVID-19.

You should ask family, friends and neighbours to support you and use online services to arrange deliveries of food and medicines where possible if you are not able or advised not to leave your home.
If this is not possible, then you can telephone a national assistance helpline 0800 111 4000 Monday to Friday during office hours (you are eligible for this if you are over 70 or receive the flu vaccine for medical reasons). Further information is also available at [https://www.readyscotland.org/coronavirus/where-to-find-additional-support/](https://www.readyscotland.org/coronavirus/where-to-find-additional-support/).

Please remember this helpline is dedicated to helping those who cannot leave their home and who cannot get help online. If you receive support from health and social care organisations, such as care support through your local authority, this will continue as normal.

What is the risk to me if I have IBD?

People receiving immune-suppression therapies, which put them at higher risk of severe illness from coronavirus (COVID-19) will receive a letter from NHS Scotland outlining more specific advice to keep themselves safe.

The following provides practical guidance on whether you might be in the high risk group or not. The risk to an individual will also take account of other factors such as age and other health conditions.

1) **High Risk**: If you are:
   - aged 70 or over
   - have a health condition such as diabetes, hypertension (high blood pressure), a respiratory condition or cardiac condition (heart disease) and are on an immunosuppressant or biologic
   - short gut syndrome requiring nutritional support
   - are on prednisolone >20mg per day or equivalent
   - have active IBD despite treatment, or
   - requirement for parenteral nutrition

2) **Moderate Risk**: If you are on an immunosuppressant or biologic without any of the above additional factors

3) **Normal Risk**: If you are on the following medications: 5ASA, rectal therapies, orally administered topically acting steroids (budesonide or beclometasone), therapies for bile acid diarrhoea (colestyramine, colesvelam, colestipol), anti-diarrhoeals (loperamide) or antibiotics for bacterial overgrowth or perianal disease.

People on the relevant immune-suppression therapies should receive a letter from NHS Scotland outlining more specific advice to keep themselves safe.

**Common biologics** include:
- Ustekinumab (Stelara)
- Vedolizumab (Entyvio)
- Infliximab (Remicade, Inflectra, Remsima, Zessly)
- Adalimumab (Humira, Amgevita, Hyrimoz, Imraldi, and Hulio)
- Golimumab (Simponi)
Common **immunosuppressants** include:
Azathioprine (Imuran, Azapress)
Mercaptopurine (6-MP)
Thioguanine (6-thioguanine)
Methotrexate (Maxtrex, Methofill, Metoject, Ebetrex, Namaxir, Nordimet and Zlatal)

If your condition falls within the highest risk group you should not wait for the NHS Scotland letter and should protect yourself immediately by following the shielding measures set out on the NHS Inform website.

Identification of people at the highest risk is ongoing, informed by centrally held data and with input from GPs and hospital clinicians. If you have questions about this please contact your local IBD team and not your GP.

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**I have not receive a letter from the NHS, but I am currently being treated for IBD, do I need to do anything differently to reduce the risk of coronavirus (COVID-19)?**

If you have not yet received a letter from NHS Scotland but using this guidance believe you fall within the **highest risk** group you are advised to protect yourself immediately by following the shielding measures set out on the NHS Inform website. You should be contacted by NHS Scotland with more information on how to access additional support, if you need it.


If you have not received a letter and do not believe you are in the highest risk group, you do not need to follow shielding measures. If you believe you meet the criteria in this guidance for **moderate risk**, you should still be particularly careful in trying to reduce the risk of becoming infected with coronavirus (COVID-19). The most up to date guidance for you is to strictly follow physical distancing measures:


If you meet the criteria set out in this guidance for **normal risk**, then there are no special or different precautions you should take compared to someone without your condition and you should follow physical distancing measures:


If you are not following shielding measures and develop symptoms of coronavirus (COVID-19) your household should follow the instructions to self-isolate:


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**Will my treatment change?**
Your treatment plan is individual to you. Your IBD team providing your care may want to review your treatment plan with you to ensure it still best suits your needs and discuss any changes that may be appropriate. This will only ever be done to reduce overall risk and harm, including the possibility of a IBD flare.

What is a flare?
A flare is when symptoms come back and you feel unwell. It will be very personal to you; the symptoms will vary from person to person and over time. The signs of flare can involve:

- 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 or mucus for more than three days
- Abdominal pain
- Just generally feel worse, especially if you have a fever
- Waking up at night to go to the toilet

I am flaring, what should I do?

- You may have a written personalised care plan, or you have agreed with your IBD team what to do if your symptoms worsen. If so, please follow the specific guidance given by your doctor or nurse.

- If you do not have a personalised plan contact your local IBD team advice line via their telephone or email. (This will have been provided to you previously.)

What to do if I am taking 5-ASAs?
If you are taking 5-ASAs and are experiencing a flare-up, you can change your medication dose without consulting your IBD hospital team, although it is important that you make sure to inform them of any changes as soon as possible (via telephone or email).

If you are taking 5-ASAs, 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

Even if your symptoms settle quickly, continue taking the higher dose for 6 weeks then reduce back to the lower dose.

If you are prescribed suppositories or enemas and you have a supply of these at home, start these as well as increasing your 5-ASA tablets. It is safe to take every night to control symptoms.
More information on 5-ASAs can be found at: https://www.crohnsandcolitis.org.uk/about-crohns-and-colitis/publications/aminosalicylates-5-asas.

If you do not experience improvement contact your local IBD team advice line by telephone or email.

**Should I still go to hospital appointments?**

If you are receiving treatment for IBD, it is important that you take extra care of your overall wellbeing, and attending hospital appointments is part of this.

Your clinical team will try to minimise the time you spend in hospital departments, for example arranging telephone or Near Me video consultations and offering blood tests at a different NHS site. Make sure your care provider has your up-to-date contact details.

Your specialist or one of their team may contact you to change your appointment. If you have not been contacted, please assume that the appointment is to go ahead as arranged.

Anyone who feels that their condition is deteriorating and they need to be seen sooner than their scheduled appointment should contact their GP or clinician who will be able to provide further advice.

Additionally, if you are unwell and require urgent care which is not COVID-19 related you should still access the care you need. This includes presenting to A&E if required, and calling your GP or hospital clinician for further advice on your condition.

If you require immediate medical attention such as if you have acute chest pain or sudden breathlessness and you need immediate medical attention call 999.

If you have symptoms of possible coronavirus (COVID-19) infection then do not come to the hospital. Instead you should check your symptoms against the information on NHS Inform https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19 and call 111 to seek further advice.

Please tell the call handler about your IBD condition. Please also inform your clinical team.

**Can I have visitors in hospital?**

Being visited by friends or relatives in hospital, or someone going with you to appointments was restricted in all but a few exceptional situations – when a person was receiving end of life care, for patients with dementia where not seeing a family member would cause distress, people with autism or a learning disability, for children, and for birth partners. Now that the level of the virus in Scotland is reducing, the restrictions on hospital visiting will be relaxed. From Monday 13 July,
each person in hospital will be permitted to have one Designated Visitor. The designated visitor can be changed if circumstances require. Visiting will be arranged with you via the care team looking after you. Visits will be made by pre-arranged appointments to ensure the number of people in the clinical area at any one time is limited to maintain a safe physical distance.

Your visitors should not bring in food parcels, flowers, helium balloons or similar items.

More information about visiting loved ones in hospital can be found here: Hospital Visiting Leaflet

**Will the symptoms be different because I have IBD and what should I look out for?**

The symptoms of coronavirus (COVID-19) will be the same as the general population.


We recommend everyone follows the NHS and Government advice about what to do if they are concerned they have come into contact with someone with confirmed coronavirus.

**Who should I contact if I become unwell or develop side effects while on my current medicines?**

All medicines have a small risk of side effects e.g. chest pain, rapid heartbeat or hives. If you feel you need emergency or urgent care telephone NHS 24 on 111 or dial 999. It is important to note that it would be unusual to develop side effects to medicines that you have been on for more than 3 months.

If you experience any side effects that cause you concern while taking your medication, contact your IBD team or your GP as soon as possible. Some signs could include: stoma blockage, not passing wind or stool, swollen tummy, severe abdominal pain, persistent vomiting, severe dehydration, high fever and rapid heartbeat.

If you are concerned that your IBD is flaring up you should seek early advice from your local IBD team, who will be keen to treat any flare early to prevent the need for hospital admission and, if possible, steroid treatment with prednisolone.

If you have previously been given advice on how to deal with a flare (such as to increase the dose of 5-ASA treatments or use topical treatment) then you should endeavour to start these as soon as possible and even before discussing with your IBD team if there is a delay in speaking to them.
If you have coronavirus (COVID-19) symptoms while you are on immune-suppressant therapy, or for any side effects of drug treatment please seek advice from your local IBD team or call 111. They will ask a series of questions and will give advice or arrange for you to have a medical review at your nearest hospital.

If you think you may have coronavirus (COVID-19), developed a new continuous cough and/or a fever/high temperature do not go to your GP, pharmacy or hospital. You should phone 111 if:

• your symptoms worsen,
• breathlessness develops or worsens,
• your symptoms haven’t improved in 7 days

Tell the call handler about your IBD.

If you have a medical emergency, phone 999 and tell them if you have coronavirus (COVID-19) symptoms.

What should I do to collect my routine medications?

You should ask family, friends and neighbours to support you and use online services.

If this isn’t possible, you can telephone the national assistance helpline 0800 111 4000 Monday to Friday during office hours. Further information is also available at https://www.readyscotland.org/coronavirus/where-to-find-additional-support/.

Please remember this helpline is dedicated to helping those who cannot leave their home and who cannot get help online.

If you receive support from health and social care organisations, such as care support through your local authority, this will continue as normal. Your health or social care provider will be asked to take additional precautions to make sure that you’re protected.

How can I maintain positive mental health?

There are simple things you can do that may help you maintain positive mental health. These include:

• Exercising regularly
• Spending time doing things you enjoy – this might include reading, cooking, other indoor hobbies or listening to/watching favourite radio or TV programmes
• Eating healthy, well-balanced meals
• Drinking enough water
• Trying to avoid smoking, alcohol and drugs
• Keeping your windows open to let in fresh air
• Arranging a space to sit with a nice view, if possible
• Getting some natural sunlight if you can or sit on your front step, staying more than 2 metres away from others
You can get support in dealing with anxiety about coronavirus (COVID-19) at:

- [https://clearyourhead.scot/](https://clearyourhead.scot/)
- [https://breathingspace.scot/](https://breathingspace.scot/)
- [https://www.samh.org.uk/](https://www.samh.org.uk/)
- [https://www.supportinmindscotland.org.uk/](https://www.supportinmindscotland.org.uk/)

If you are self-isolating and experiencing much higher levels of distress than is normal for you and you are struggling to cope with day-to-day things this might be useful:


NHS Inform has further resources to help your mental wellbeing:


### Are my carers, and/or friends and family still allowed to visit my home?

At the moment, people are permitted to use public outdoor spaces for recreational purposes, for example to sit in a public space and one household can meet up with up to two households outdoors, no more than 8 at one time, including in gardens, but with physical distancing required. People can now travel beyond 5 miles if individuals are acting in line with other guidance.

If you have a carer or visitor who supports you with essential everyday tasks, they are still able to come to your home. We do advise that upon arrival, and often throughout their visit, they wash their hands for at least 20 seconds.

It’s also a good idea to speak to your carers about what happens if one of them becomes unwell.

If you need help with care but you’re not sure who to contact, your local council should be able to help you or please visit [https://careinfoscotland.scot/topics/how-to-get-care-services](https://careinfoscotland.scot/topics/how-to-get-care-services)

### What should I do if I am a carer for someone with IBD?

Coronavirus (COVID-19) can have serious effects on anyone who has a long-term health condition or a weakened immune system, including some people with IBD.

If you’re caring for someone who’s vulnerable, there are some simple steps that you can take to protect them. You should follow advice on good hygiene, such as:

- Wash your hands on arrival and often - use soap and water for at least 20 seconds or use hand sanitiser
- Cover your mouth and nose with a tissue or your sleeve (not your hands) when you cough or sneeze

Update to advice for those who have not been asked to shield

As the prevalence of the virus in Scotland reduces and the level of risk lowers, some of the restrictions imposed are being gradually eased. You can keep up to date with any changes here: https://www.gov.scot/collections/coronavirus-covid-19-scotlands-route-map/

It’s important to remember however, that those over the age of 70 without an underlying health condition and under the age of 70 who receive the flu jab for medical reasons are still classed as being at an increased risk from severe illness from COVID-19 and should be particularly careful in following physical distancing measures along with hand washing and cough hygiene.