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## 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 and/or a fever/high temperature (37.8C 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 at extremely high risk of severe illness with COVID-19. If you are in this group you will receive a letter from NHS Scotland or be contacted by your doctor and should follow shielding measures: <https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19/coronavirus-covid-19-shielding>**

## 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 call for support?

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

The NHS Inform Scotland website has up-to-date information and answers to frequently asked questions.

<https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19>

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

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.

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>.

## 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, colesevelam, 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)

Tioguanine (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.

<https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19/coronavirus-covid-19-shielding>.

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.

**I am part of the group who are identified as at higher risk of illness and got a letter from the NHS. Is there something I need to do differently to reduce the risk of Coronavirus?**

The safest course of action is for you to stay at home at all times and avoid all face-to-face contact for at least twelve weeks, except from carers and healthcare workers who you must see as part of your medical care. The rest of your household should support you to stay safe and closely follow guidance on social distancing, reducing their contact inside and outside the home. This will help protect you by stopping you from coming into contact with the virus.

**Things you should be doing to stay safe.**

You, or the person you care for, should:

- **DO STRICTLY AVOID** contact with anyone who is displaying symptoms of coronavirus (COVID-19). These symptoms include high temperature (above 37.8 °C) and/or a new and continuous cough. You might want to have a thermometer at home to check your temperature if you are worried that you may have a fever.
- **DON'T** leave your home.
- **DON'T** attend any gatherings. This includes gatherings of friends and families in private spaces e.g. family homes, weddings and religious services.
- **DON'T** go out for shopping, leisure or travel. When arranging food or medication deliveries, these should be left at the door to minimise contact.
- **DO** keep in touch using remote technology such as phone, internet, and social media.
- **DO** use telephone or online services to contact your GP (for non-coronavirus issues) or other essential services.
- **DO** regularly wash your hands with soap and water for 20 seconds. Ask carers or support workers who visit your home to do the same.

The rest of your household need to support you to stay safe and must stringently follow guidance on social distancing, reducing their contact outside the home.

In your home, you should:

- minimise the time you spend with others in shared spaces (kitchen, bathroom and sitting areas) and keep any shared spaces well ventilated
- aim to keep 2 metres away from others and encourage them to sleep in a different bed where possible
- use separate towels and, if possible, use a separate bathroom from the rest of the household, or clean the bathroom with cleaning products after every use

- avoid using the kitchen when others are present, take your meals back to your room to eat where possible, and ensure all kitchenware is cleaned thoroughly using a dishwasher at the 60 degrees setting if possible, otherwise in very warm soapy water.

If the rest of your household are able to follow this guidance to help keep you safe, there is no need for them to wear any special medical clothing or equipment.

### **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?**

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.

<https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19/coronavirus-covid-19-shielding>.

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 social distancing measures:

<https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19/coronavirus-covid-19-general-advice>

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 social distancing measures: <https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19/coronavirus-covid-19-general-advice>

If you are not following shielding measures and develop symptoms of Coronavirus/Covid-19 your household should follow the instructions to self-isolate: <https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19/coronavirus-covid-19-guidance-for-households-with-possible-coronavirus-infection>

### **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 IBD team will try to minimise the time you spend in hospital departments and may contact you to change your appointment, 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.

If you have the slightest sign of having Coronavirus/COVID-19 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 hospital IBD team.

Being visited by friends or relatives in hospital, or someone going with you to appointments is now restricted unless essential. The following visits are deemed essential:

- a person receiving end-of-life care
- to support someone with a mental health issue such as dementia, a learning disability or autism where not being present would cause the patient to be distressed
- to accompany a child in hospital

If relatives or friends need to visit you, it is vital that they wash their hands for at least 20 seconds on arrival and often after that.

If hospital admission is likely please remember to pack your mobile phone and phone charger so you can keep in touch with relatives and friends.

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

The symptoms of Coronavirus will be the same as the general population.

NHS Inform Scotland provides up to date advice about Coronavirus/COVID-19 <https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19>

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, then the public sector, business, charities, and the general public are putting arrangements in place to help those advised to stay at home. It's important to speak to others and ask them to help you to make arrangements for:

- food
- medicines



- essential services and supplies
- looking after your physical health, mental health and wellbeing

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.

### **As we are being asked to stay at home for a prolonged period, how can I maintain a positive mental health?**

We understand that the situation you may be facing at the moment, due to Coronavirus/COVID-19 and your health condition can increase anxiety.

There are simple things you can do that may help, to stay mentally and physically active during this time, such as:

- Exercise regularly - look for ideas of exercises you can do at home
- Spend time doing things you enjoy – this might include reading, cooking, other indoor hobbies or listening to/watching favourite radio or TV programmes
- Eat healthy, well-balanced meals
- Drink enough water
- Try to avoid smoking, alcohol and drugs
- Keep your windows open to let in fresh air
- Arrange a space to sit with a nice view, if possible
- Get some natural sunlight if you can or sit on your front step, staying more than 2 metres away from others

Support in dealing with anxiety around impacts of Coronavirus can also be found at:

<https://breathingspace.scot/>

<https://www.samh.org.uk/>

<https://www.supportinmindscotland.org.uk/>

Tips on how to cope if you are worried about Coronavirus and in isolation can be found at:

<https://learn.nes.nhs.scot/28084/coronavirus-covid-19/psychosocial-support-and-wellbeing/tips-on-how-to-cope-if-you-are-worried-about-coronavirus-and-in-isolation>

NHS Inform has further resources to help your mental wellbeing:

<https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19>

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

You should let your regular visitors know that you are reducing social contacts and they shouldn't visit you during this time, unless they are providing essential care for you. Essential care includes things like help with washing, dressing, or preparing meals.

If you receive regular health or social care from an organisation, either through your local authority or paid for by yourself, inform your care providers that you are reducing social contacts and agree a plan for continuing your care.

If you receive essential care from friends or family members, these carers can continue to visit. Carers will be provided with gloves and facemasks to reduce the risk of passing on infection.

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.

If you need help with care but you're not sure who to contact please visit <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
- Put used tissues in the bin immediately and wash your hands
- Don't visit if you're unwell and make alternative arrangements for their care
- Provide them information on who they should call if they feel unwell (their GP phone number and 111) and how to use NHS inform
- Access advice on creating a contingency plan from Carers UK
- Find out about different sources of support that could be used
- Look after your own well-being and physical health