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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, loss of sense of smell or taste 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 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 been contacted by your doctor. If you are in this group you should be following shielding advice which is to strictly follow physical distancing and hygiene measures. More information can be found here:

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

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

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.

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).

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.

A national helpline has been set up to provide essential assistance to those who don't have a network of support

If you are unable to access the food and essentials you need, or if you cannot afford to buy them, please phone the national helpline on 0800 111 4000, or contact via textphone on 0800 111 4114. The helpline is open office hours Monday to Friday and will connect you to your local authority who can help provide support or signpost on to other organisations to help you. Further information on the range of support available can be found at <https://www.mygov.scot/coronavirus-covid-19/>.

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 and you have not received a letter you should follow 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>.

If you have questions about this please contact your local IBD team and not your GP.

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)?

Everyone should be following physical distancing measures to reduce the transmission of COVID-19. From the 1 August shielding has been paused. Most people who were shielding can now follow the [advice for the general population](#), however, you should strictly follow [physical distancing and hygiene measures](#). You may also want to think about the levels of risk associated with work and daily activities.

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

If you did not receive a letter, you may still be considered at a higher risk than the general population so it's important you are careful in trying to reduce the risk of becoming infected with coronavirus (COVID-19). You should follow the most up to date guidance on physical distancing, which will protect you and others from picking up the virus:

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

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?

Information about visiting loved ones in hospital can be found [here](#).

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.

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

A national helpline has been set up to provide essential assistance to those who don't have a network of support

If you are unable to access the food and essentials you need, or if you cannot afford to buy them, please phone the national helpline on 0800 111 4000, or contact via textphone on 0800 111 4114. The helpline is open office hours Monday to Friday and will connect you to your local authority who can help provide support or signpost on to other organisations to help you. Further information on the range of support available can be found at <https://www.mygov.scot/coronavirus-covid-19>.

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://breathingspace.scot/>
- <https://www.samh.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:

<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>

When could I expect to receive the vaccine? (Amended 18th January)

Your local NHS health board or GP will invite you for your coronavirus vaccine soon (or will already have done so) if you are in one of these groups:

- residents in a care home for older adults and their carers
- people aged 80 and over
- frontline health and social care workers

After these groups have been invited for their vaccine, further groups at higher risk from coronavirus will be invited. You will be offered an appointment as soon as it's possible for you to get the vaccine. To find out more visit

www.nhsinform.scot/covid19vaccine or call the Scottish COVID-19 Vaccination Helpline on 0800 030 8013 (open daily, 8am to 8pm).

What do I need to know about the vaccine? (Amended 18th January)

- The coronavirus (COVID-19) vaccine does not cause a coronavirus infection. It helps to build up your immunity to the virus, so your body will fight it off more easily if it affects you.
- This can reduce your risk of developing coronavirus and make your symptoms milder if you do get it.
- The coronavirus vaccine is suitable for people with disorders of the immune system.
- The effectiveness and immune response of the vaccine is being monitored as the vaccine is rolled out.

How are the vaccines given?

The coronavirus (COVID-19) vaccine will be given in 2 doses. It offers good protection within 2 to 3 weeks of the first dose.

The latest evidence suggests the first dose of the vaccine provides protection for most people for up to 12 weeks. As a result of this evidence, when you can have the second dose has changed. This is also to make sure as many people can have the vaccine as possible.

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

The current guidance on meeting up with others is [here](#).

If you have a carer or visitor who supports you with essential everyday tasks, they can 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>.

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

Advice for unpaid carers is available at:

<https://www.gov.scot/publications/coronavirus-covid-19-advice-for-unpaid-carers/>.

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

You can keep up to date with any changes [here](#).

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.