



Date: 8 April 2020

Coronavirus (COVID-19) – Important advice for people with a Rare Condition

This leaflet will provide information for you and your family about how Coronavirus/COVID-19 might affect you if you have a rare disease.

The most common symptoms of Coronavirus/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 hospital services where possible. The NHS will continue to provide vital cancer treatments, and emergency and urgent care for all patients. With that in mind we have listed some important information below. This advice includes answers to questions you may have and details on 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. If you are in this group you 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 rare disease?

The main target of the Coronavirus (COVID-19) is the lungs. As a result, some people with a rare disease are more at risk of becoming ill if they contract Coronavirus (COVID-19).

As a result, some people with a rare disease, such as those listed below, are more at risk of becoming ill if they contract Coronavirus (COVID-19):

- People on immunosuppression therapies sufficient to increase risk of infection
- People with a rare disease, including all forms of Interstitial Lung Disease/Sarcoidosis and inborn errors of metabolism that significantly increase the risk of infections such as Severe Combined Immunodeficiency (SCID) and Homozygous Sickle Cell (not trait)
- People with Cystic Fibrosis

Where can I call for support?

If you have concerns about your condition or your treatment you should contact your clinical team or your GP.

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

www.nhsinform.scot/coronavirus

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

For other non-emergency health concerns, your first point of contact should still be your GP or 111. They are likely to assess you over the telephone or via video link rather than in person to reduce the risk of infection from Coronavirus (COVID-19).

Will my treatment change?

Your treatment plan is individual to you. You should not change your medication unless told to by your GP or specialist. This is also true if you are being treated with immunosuppressants.

Should I still go to hospital appointments?

It is vital that if you are receiving treatment for a rare condition that you take extra care of your overall wellbeing, and attending appointments in a different way 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 the appointment is to go ahead as arranged.

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 rare condition. Please also inform your clinical specialist 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.

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 (COVID-19)?

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 or the person you care for should be doing and not doing to stay safe.

- **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 physical contact with other people 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 received a letter from the NHS, but I am currently being treated for a rare disease, 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 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 will 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 the shielding measures but you should still be particularly careful in trying to reduce the risk of becoming infected with Coronavirus/ COVID-19.

You should follow the most up to date guidance on social 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>

If you 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 the symptoms be different because I have a have a rare disease and what should I look out for?

The symptoms of Coronavirus will be the same as the general population but there may be worsening of respiratory condition symptoms such as breathlessness.

If this happens you will need to speak to your specialist team or GP. They will be able to advise or seek advice from appropriate medical professionals.

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

If you need immediate medical attention call 999. If you feel that your rare disease symptoms are worsening contact your GP.

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 respiratory condition.

If you have a medical emergency, phone 999 and tell them 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 gearing up 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.

What should I do if I am a carer for someone with a rare disease?

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 a rare disease.

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

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 (COVID-19) 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 (COVID-19) 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, unless they have any of the symptoms of Coronavirus (COVID-19). 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>

Other Useful Information

<https://www.sparn.scot.nhs.uk/>