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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, 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 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 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/>

If you have a rare disease AND have been asked to shield you will find further information on different types of conditions e.g. respiratory, cancer, here: <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 rare disease?

The main target of the coronavirus (COVID-19) is the lungs.

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

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

The symptoms of coronavirus (Covid-19) 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.

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 at www.nhsinform.scot/coronavirus

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/>.

Further information is also available at:

<https://www.readyscotland.org/coronavirus/where-to-find-additional-support/>

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.

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 coronavirus (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 rare condition. Please also inform your clinical specialist team.

Can I be visited 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 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](#)

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 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)?

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>

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>

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, a fever/high temperature and/or a loss of sense of taste or smell, 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 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?

If you need to collect your routine medication its important you follow strict physical distancing when doing so. You could also ask family, friends and neighbours to support you and use online services to have it delivered.

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.

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 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>

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 at increased risk, 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

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>

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

You can keep up to date with any changes here:

<https://www.gov.scot/collections/coronavirus-covid-19-scotlands-route-map/>

See also <https://www.gov.scot/publications/coronavirus-covid-19-phase-3-staying-safe-and-protecting-others/pages/overview/>

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.

Other Useful Information

- **Scottish Paediatric and Adolescent Rheumatology Network (SPARN):**
<https://www.sparn.scot.nhs.uk/>
- **Scottish Paediatric and Adult Haemoglobinopathies Network (SPAH):**
<https://www.spah.scot.nhs.uk/>