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 receive a letter from NHS Scotland or be contacted by your doctor. If you are in this group you should currently be following shielding measures: 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 are in this group there have been some changes to our shielding advice. The links above have been updated to reflect these changes but we have also listed them here.

People who have been identified as needing to shield and who live at home, are now advised to:

- stay at home as much as they can
- avoid going places that are indoors
- only leave their home to be active or meet with people from another household outdoors
- keep 2 metres away from everyone, even those they live with

This means that, if you want to you

- can go for a walk, wheel, run or cycle
- can go out on your own, with someone you live with, or your usual carer
- should maintain strict physical distancing, also known as social distancing, at all times, even if you live with the person you’re out with
- can meet with people from one other household outdoors each day, in groups of no more than 8 people
- try to choose times and areas that are quiet, if you can
- should stay close to home so you do not have to use a toilet that is not your own
- should wash your hands for at least 20 seconds as soon as you get back home

**Why is the advice changing for people who have been asked to shield?**

We have changed our advice because we now know that the risk of getting infected with coronavirus (COVID-19) outdoors is very low if:

- infection rates in Scotland are low enough
- you stay 2 metres away from other people

Going out for exercise can also have real benefits for your physical and mental health.

**Other ways shielding might change in the future**

All other shielding advice and support remains in place until 31 July.

We know that you may have mixed feelings about this advice. That’s why we want to tell you as much as we can about how shielding might change in the future. We are learning about the virus all the time, and about what increases or reduces the risk to you and to others. Over the summer, we will work towards:
• giving you updated clinical evidence about your conditions and what that means for your risk from coronavirus,
• helping you understand the changing infection rate in your local area
• giving this information in a way that is accessible, understandable and helpful,
• giving you access to support that can help you make informed choices about your life,
• supporting you to put your choices into practice.

We will do this because shielding will be having a huge impact on your life and the lives of your loved ones. It’s important that you are given the chance to consider and make informed decisions about what matters to you.

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

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

A national helpline has been set up to provide essential assistance to those who don’t have a network of support but who are in the ‘increased risk’ group.

If you are over 70, disabled, require the support of mental health services, are pregnant or receive a flu jab for health reasons you can call the national assistance helpline on 0800 111 4000 Monday to Friday 9:00am – 5:00pm. This national helpline has been set up to provide essential assistance to those who cannot leave their home and who do not have family or existing community support or cannot get help online.

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).

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 arrangements have been made for:

- **those classed in the highest risk group** to register for support via a text service, details will be sent to you in a letter from NHS Scotland advising you to shield yourself at home (you are in this group if you have a qualifying health condition and/or are prescribed immune-suppressant therapies) [https://www.gov.scot/publications/covid-shielding-contacts/pages/highest-risk-classification/](https://www.gov.scot/publications/covid-shielding-contacts/pages/highest-risk-classification/)

- **those classed at increased risk** to 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.

**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.

Being visited by friends or relatives in hospital, or someone going with you to appointments is 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 highest 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 paragraphs at the beginning of this guidance tell how the advice for this group is changing and to what extent.

To stay safe, we advise that you:

• stay at home as much as possible – you can go into a private garden or sit on your doorstep
• go outside only to exercise or to meet with up to 7 people from one other household a day – this does not yet apply if you live in a residential care or nursing home
• keep in touch with family and friends using technology such as phone, internet, and social media
• don’t go out for shopping or to pick up prescription medication – please arrange for these to be delivered by someone you know, through a supermarket or by your local authority
• If you choose to leave your home to go outside, we advise that you:
  • do whatever level of physical activity feels comfortable for you
  • try to avoid touching objects and surfaces
  • keep 2 metres (3 steps) from other people as much as possible, even if you are out with someone you live, or with your usual carer
  • try to choose times and areas that are quiet
  • stay close to home so you do not have to use a toilet that is not your own
  • wash your hands for at least 20 seconds as soon as you get back home

Alongside this, the rest of your household can support you to stay safe by closely following guidance on physical distancing, reducing their contact inside and outside the home. This will help protect you by stopping you from coming into contact with the virus.

In your home, we advise that you all try to:

• 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 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
• 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 and contact your GP or Clinician for advice.

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 physical distancing, which will protect you and others from picking up the virus:


If you develop symptoms of coronavirus (Covid-19) your household should follow the instructions to self-isolate:


**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.

**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?

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 arrangements have been made for:

- **those who have been asked to shield** can register for support via a text service, details will be sent to you in a letter from NHS Scotland advising you to shield yourself at home (you are in this group if you have a qualifying health condition and/or are prescribed immune-suppressant therapies) [https://www.gov.scot/publications/covid-shielding-contacts/pages/highest-risk-classification/](https://www.gov.scot/publications/covid-shielding-contacts/pages/highest-risk-classification/) or

- **those classed at increased risk** but have not been asked to shield can telephone the 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.

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 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 outdoors following the guidelines above or indoors. 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://clearyourhead.scot/
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:

NHS Inform has further resources to help your mental wellbeing:

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

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 – outdoors following the guidelines above or indoors. 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
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Support in dealing with anxiety around impacts of Coronavirus (COVID-19) can also be found at:
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Tips on how to cope if you are worried about Coronavirus (COVID-19) and in isolation can be found at:

NHS Inform has further resources to help your mental wellbeing:

Unless someone is providing essential care for you should reduce you social contact with them. 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
Update to advice for those who have not been asked to shield

On the 18 June the advice for those who aren’t shielding changed.

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/