



Date: 07 August 2020

Coronavirus (COVID-19) - Important shielding advice for people with a rare condition

This leaflet provides you and your family with information about changes to shielding. It might affect you if you have a rare disease.

There are many conditions classed as a rare disease. Not everyone with a rare disease will be in the shielding group. If you are part of the shielding group you will have received a letter from the Chief Medical Officer (CMO) or been contacted by your doctor or specialist clinician.

This document is not intended for children or young people who are part of the shielding cohort. In this situation, you should contact your hospital based clinical team for advice.

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 immunity that significantly increase the risk of infections such as Severe Combined Immunodeficiency (SCID) and Homozygous Sickle Cell (not trait)
- People with Cystic Fibrosis

If you think you have coronavirus (COVID-19)

Although it is highly unlikely you will catch coronavirus (COVID-19) you should watch out for symptoms. The most common symptoms 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.

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 you do have symptoms you should call 111 as soon as possible.

You should tell the call handler about your condition.

If you have a medical emergency, whether related to coronavirus or not, you should phone 999.

Where can I call for support about my condition or treatment?

If you have concerns about your condition or your treatment you should contact your GP or your specialist clinician.

Where can I call for support about shielding?

If you have concerns about your condition or your treatment you should contact your GP or specialist clinician.

If you need to ask someone a question about shielding support or anything else, you can call the free national helpline number on 0800 111 4000. The helpline is open Monday to Friday, from 9am to 5pm, and will put you in touch with someone from your local council.

The NHS Inform Scotland website has up-to-date information and answers to frequently asked questions: www.nhsinform.scot/coronavirus

Further information is also available at:

- Ready Scotland: <https://www.readyscotland.org/coronavirus/where-to-find-additional-support/>.
- Genetic Alliance UK: <https://geneticalliance.org.uk/>
- Rare Disease UK: <https://www.raredisease.org.uk/>

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).

Pausing Shielding

Shielding was paused on 1 August. This is because the levels of infection in Scotland are low enough for us to do this.

This means that in general, people who have been shielding can now follow the same advice as the rest of Scotland.

The number of people in Scotland with coronavirus is much lower. However, people who have been asked to shield still have the same risk if they become infected with the virus.

You should continue to strictly follow physical distancing and hygiene measures. You may also want to think about the levels of risk associated with what you are choosing to do. You can then decide how comfortable you are with that risk

Full details on what you can do from the 1 August can be found here:

www.gov.scot/publications/covid-shielding

You can also find the advice for the rest of Scotland here:

www.gov.scot/publications/coronavirus-covid-19-what-you-can-and-cannot-do

This guidance will be kept updated with any changes.

Changes to support

Now that shielding is paused, the [weekly grocery boxes](#) have stopped.

[Priority access to supermarket online delivery slots](#) will continue to anyone who had signed up before 31 July.

Your local authority will be able to offer more support if you cannot afford food. You can contact them via the free national helpline on 0800 111 4000.

Keeping informed

Even though shielding is paused, we will continue to provide information and advice.

You will be able to access help and support online and we will continue to update this.

Different things matter to different people. We want to help you to make informed choices based on your own individual circumstances. Our online support includes:

- [this guidance about the conditions for the six main shielding categories](#)
- [guides to help you understand what sort of activities are safer than others](#)
- [tools to help you protect yourself during daily activities](#)
- a [workplace risk assessment tool](#) to help you consider your individual risk when returning to work
- guidance on [returning to school](#)

We will also keep sending updates through the [SMS Shielding Service](#), which will include a new Covid forecasting service for shielding. This will allow people who have been shielding to sign up to an SMS update that tells them about their risk of being exposed to Covid in their local area.

The SMS Shielding Service and the national helpline will be available for as long as it is needed. If it's no longer needed, we'll give you plenty of notice that it's ending.

If the infection rate in Scotland goes up

The infection rate in Scotland may rise as well as fall in the coming months. Small changes will not affect this advice, but if we start to see an increase in the infection rate that concerns us, we may advise you to take extra steps to stay safe. If we need to, we'll let you know by letter and through the SMS Shielding Service.

As we keep on improving our knowledge about COVID-19, we're also reviewing evidence about who needs to take extra steps to stay safe. If we find out about a change that affects you, we will contact you.

Personal clinical advice

Before the virus, clinicians advised some individuals to avoid doing certain things. This is because of their specific health condition or specific treatments. You should continue to follow any specific advice that your clinician provides. This is because they know you personally.

This does not mean you are being advised to shield again because of an increase of coronavirus. You should discuss this with your healthcare team if you are unsure about any health advice.

Lowering your risk

Now the virus is under control it is safer for people who have been shielding to return to day-to-day life.

Our ['Quick Guide to Risk'](#) sheet lists examples of everyday activities that are 'low risk' and 'higher risk'. There are also [things you can do to lower your risk](#). We'd advise you to keep these risks in mind when choosing what to do and where to go.

There are ways to lower your risk of exposure to the virus as you start doing more activities outside your home. It is important to:

- follow physical distancing guidance and keep 2 metres away from people – except from people you live with or are in your extended household group
- wear face coverings inside shops and on public transport
- wash your hands regularly and for at least 20 seconds
- clean hard surfaces
- cover your mouth to cough either into a tissue you can dispose of straightaway or into a bent elbow
- try to avoid touching your face as much as you can
- avoid contact with anyone who has the symptoms of COVID-19

Face coverings

Face coverings reduce the risk of the wearer passing on the infection. This is why it is now mandatory to wear face coverings inside shops and on public transport. We recommend that you wear a face covering when physical distancing is difficult. The best way to lower your risk is to maintain physical distancing as much as possible. It is also best to avoid busy or crowded places.

There could be reasons why you may not be able to wear a face covering. This could be because a face covering would cause you difficulty, pain or severe distress. This might be due to a health condition or disability. You do not need proof of this.

Frequently Asked Questions about 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?

Yes, it is important to continue to attend your hospital and GP appointments.

You may receive your care in a different way to minimise the time spent in hospital departments. They might arrange for you to have a telephone or video consultations or get your blood tests at a different NHS site. Make sure you have provided up-to-date contact details.

If you feel that your condition is deteriorating and you need to be seen sooner than your scheduled appointment, you should contact your GP or clinician for further advice.

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 going to A&E if required, or calling your GP or specialist clinician for further advice on your condition.

If you have acute chest pain or sudden breathlessness or need immediate medical attention call 999.

What if I have symptoms of coronavirus (COVID-19)?

If you have symptoms of possible coronavirus (COVID-19) infection then do not go to the hospital or your GP. 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 immediately.

Please tell the call handler about your condition. Please also inform your specialist clinician.

Can friends and family visit me in hospital?

Yes, each person in hospital is allowed to have one Designated Visitor. A Designated Visitor is someone you would like to be your named visitor. This might be your spouse, next of kin or a friend.

You can change your designated visitor. 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 hospital at any one time is limited to maintain a safe physical distance.

Your visitors should not to 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 you are likely to go to hospital 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)?

If you have not received a letter from NHS Scotland but believe you fall within the highest risk group you are advised to stay safe by:

- following the latest guidance about physical distancing – at the moment, physical distancing advice is for you to stay 2 metres away from anyone you do not live with
- washing your hands regularly and for at least 20 seconds
- trying to avoid touching your face, as much as you can
- avoiding contact with anyone who has the symptoms of coronavirus (COVID-19). These include new continuous cough, fever or loss of, or change in, sense of smell or taste (anosmia).

Further information can be found on NHS Inform:

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

You should contact your GP or specialist clinician for advice.

Do people who live with me need to do anything differently to keep me safe?

You and your household should continue to follow strict physical distancing and hygiene measures. All members of your household must [self-isolate](#) if someone develops COVID-19 symptoms.

How do I stay safe whilst visiting people?

You can now meet people both indoors and outdoors, with physical distancing. This can include overnight stays. This can be at different times and can also be different households each day.

When meeting people from other households:	When meeting people inside:	When meeting people outside:
<ul style="list-style-type: none">• maximum of 4 other households per day	<ul style="list-style-type: none">• up to 8 people from 2 other households	<ul style="list-style-type: none">• up to 15 people from 4 other households
<ul style="list-style-type: none">• stay 2 at least metres away from anyone you do not live with	<ul style="list-style-type: none">• everyone should wash their hands as soon as they arrive, often during their visit and	<ul style="list-style-type: none">• choose times and areas that are quiet• avoid touching hard surfaces such as gates,

<ul style="list-style-type: none"> • wear a face covering if it is not possible to maintain physical distancing • do not share food or utensils – each household should bring and eat their own food • do not meet with anyone who has coronavirus symptoms 	<p>again as soon as they get home</p> <ul style="list-style-type: none"> • avoid touching hard surfaces such as door handles and bannisters with your hands • sit away from people you do not live with • open the windows 	<p>walls and park benches with your hands</p> <ul style="list-style-type: none"> • wash your hands for at least 20 seconds as soon as you get home
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You can now also choose to [attend larger gatherings](#). This includes weddings, funerals and worship. The more people you come into contact with, the higher the risk is of being exposed to the virus. Please think about this when deciding to attend a larger gathering.

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). Essential care includes things like help with washing, dressing, or preparing meals.

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>

How do I stay safe whilst outdoors?

Before leaving home, plan how you will keep safe and minimise risk by considering:

- taking an alcohol-based hand rub (hand sanitiser) with you
- taking tissues and a separate bag to keep used tissues
- taking a face covering
- choosing times and areas that are quiet

When outdoors, try to:

- use a hand sanitiser often, especially before eating or after touching surfaces
- stay at least 2 metres away from anyone you do not live with
- wear a face covering if it is not possible to maintain physical distancing
- avoid touching hard surfaces such as gates, walls, fences and park benches with your hands as much as possible
- wash your hands for at least 20 seconds as soon as you get home

Some business in the retail and hospitality sections are now able to introduce 1 metre zones. This is only allowed if the business takes [steps to reduce risks](#) to keep their customers safe. There will be clear signage outside the building. You may want to avoid entering if you do not feel comfortable.

Our '[Quick Guide to Risk](#)' sheet lists examples of everyday activities that are 'low risk' and 'higher risk'. There are also [things you can do to lower your risk](#). We'd advise you to keep these risks in mind when choosing what to do and where to go.

Can I use public transport?

You can choose to use public transport. To lower your risk, try to:

- avoid travelling at peak times when it will be busy
- put on your face covering before getting on public transport
- avoid touching any handle rails or wiping them before use
- sit near an open window if you can
- wash your hands as soon as you can once you get to your destination

Transport Scotland have provided more [detailed travel guidance](#).

How can I stay safe when staying in holiday accommodation?

You can choose to stay in any type of holiday accommodation and travel to second homes. This can be with the people who live with, or people in your extended household.

Self-catering accommodation includes anywhere that does not have shared facilities. It must also be accessible via an external door.

We have produced [guidance for the hospitality industry](#) which includes hygiene precautions. This includes regular disinfection of objects and surfaces that are touched regularly. You may wish to check what hygiene measures are in place with the provider beforehand.

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?

You can now book GP and NHS appointments as normal. If you feel worried and want to speak to someone, your GP or other healthcare provider can help make sure you get the support you need.

You can also find help online from the Scottish Association of Mental Health (SAMH) at www.samh.org.uk and over the phone from:

- Breathing Space - 0800 83 85 87
- Samaritans - 116 123

NHS Inform also has resources to help your mental wellbeing:

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