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Coronavirus (COVID-19) – Important advice for people with rheumatic conditions

This leaflet provides you and your family with information about how coronavirus (COVID-19) might affect you if you have a rheumatic condition.

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 (37.8C 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 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 rheumatic conditions?

It is possible that some people with some rheumatic conditions disease may have a higher risk of becoming severely ill if they have coronavirus (COVID-19) because they are on drugs that suppress their immune system. 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.

Where can I get support?

If you have concerns about your condition or your treatment you should contact your rheumatology 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).

Versus Arthritis also has useful information at:

<https://www.versusarthritis.org/news/2020/march/coronavirus-covid-19-what-is-it-and-where-to-go-for-information/>.

Further information about COVID-19 for children or young people with rheumatic conditions is available at the Scottish Paediatric and Adolescent Rheumatology Network (SPARN) <https://www.sparn.scot.nhs.uk/>.

There is also further advice available on Parent Club on how to support your child at this difficult time. <https://www.parentclub.scot/topics/health/coronavirus>.

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 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/>.

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 is the risk to me if I have a rheumatic condition?

It is not known if having rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, SLE, Sjogrens syndrome, connective tissue disease or vasculitis increase the risk of contracting Covid-19 in themselves. However it is possible that the risk of developing severe illness may be increased in people receiving certain drug treatments that suppress the immune system (immunosuppressives).

This does not apply to all drugs but you may be at higher risk of severe illness from coronavirus (COVID-19) if you are on steroid medication (prednisolone) and/or other immunosuppressant medication. It is difficult to provide a precise estimate of how much these drugs increase the risk for individual patients.

The following has been informed by guidance produced by the British Society for Rheumatology and provides practical guidance on whether you might be in the highest risk group or not. The risk to an individual will also take account of other factors such as age and other health conditions.

- 1) **Highest Risk:** If your medication includes steroids (prednisolone typically >20mg daily or less in combination with other drugs), cyclophosphamide, or combinations of immunosuppressive drugs and biologic medications and you also have heart disease, lung disease, kidney disease, diabetes or are aged over 70 years.
- 2) **Increased Risk:** If your disease is well controlled with biologic or immunosuppressive therapy but you are not on steroids, you are on no more than 2 immunosuppressive drugs, you are under 70 years of age and you do not have any additional health problems.
- 3) **Low or Normal Risk:** You are at low risk if your disease is well controlled and you are on no long term medication, or taking only Sulfasalazine or Hydroxychloroquine.

If your condition falls within the highest risk group you should follow the shielding advice 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 hospital rheumatology team and not your GP.

I did not receive a letter from the NHS, but I am currently being treated for a rheumatic condition, 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. You should not change your medication unless told to by your GP or rheumatologist. If you develop symptoms of any infection, seek advice from your rheumatology team, as they may advise you to alter your medication. If you are on steroid medication (prednisolone) **you should not stop that suddenly.**

Should I still go to hospital appointments?

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 rheumatic condition. Please also inform your clinical team.

Can I have visitors in hospital?

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

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

If you have chest pain, significant bleeding or you need immediate medical attention call 999.

If you have symptoms of coronavirus (COVID-19) while you are on immunosuppressive therapy, or for any side effects of drug treatment, 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. You should mention all your medication, including any treatment that is given by injection or infusion.

All people, including those aged 16 years and under, should continue to take their medication unless directed otherwise by their rheumatology team or GP. If you are planning to start or switch to a new medication this may now need to be reviewed. Please remember if you are taking steroids (prednisolone) you **should not stop these suddenly**.

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 rheumatic condition.

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 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

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.
- Versus Arthritis has created a shared decision making support tool which you may wish to use. - [msk-rheumatology-decision-support-tool-covid-19-vaccines-final-15012021.pdf](https://www.versusarthritis.org/decision-support-tool-covid-19-vaccines-final-15012021.pdf) (versusarthritis.org)

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.

What should I do if I am a carer for someone with a rheumatic condition?

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 rheumatic condition.

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/>

Should I stop my medication if I think I may be infected with the virus?

It depends - your treatment plan is individual to you. You should not change your medication unless told to by your GP or rheumatologist. If you develop symptoms of any infection, seek advice from your rheumatology team, as they may advise you to alter your medication. For those on glucocorticoids (steroids, prednisolone), the expectation is that treatment **should not be stopped abruptly**.

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>

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>.

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

You can keep up to date with any advice [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.