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

This leaflet provides you and your family with information about how coronavirus (COVID-19) might affect you if you have a neurological 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. With that in mind we have listed some important information below. This includes answers to questions you may have and directions to 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 neurological conditions?

Some people with a neurological condition are in the group that is at highest risk of becoming ill if they have coronavirus (COVID-19) because their immune system is weakened. 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.

The Association of British Neurologists also has useful information for people with neurological conditions: <https://www.theabn.org/page/COVID-19>.

Where can I get support?

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

If you are the parent or carer of a child or young person with this condition you will be particularly anxious about what you should and can do to help and protect them at this time. Alongside the clinical advice provided in this leaflet there is 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 coronavirus (COVID-19).

The possible effects of coronavirus (COVID-19) on patients using medication for multiple sclerosis are dealt with in detailed guidelines from the Association of British Neurologists and can be accessed at:

https://cdn.ymaws.com/www.theabn.org/resource/collection/65C334C7-30FA-45DB-93AA-74B3A3A20293/NEW_Version_ABN_Guidance_on_DMTs_for_MS_and_COVID19_APPROVED_18_March_v_3.pdf

The Neurological Alliance of Scotland has published advice at <https://www.scottishneurological.org.uk/covid-19-info/>. This also includes links to organisations publishing conditions specific information, advice and support.

Cerebral Palsy Scotland has also published advice at <https://cerebralpalsyscotland.org.uk/coronavirus-covid-19-and-cerebral-palsy/>.

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 you can 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/>.

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.

What is the risk to me if I have a neurological condition?

The following neurological conditions are potentially associated with high risk.

Multiple Sclerosis

Specific circumstances of high risk are:

- High risk immunosuppression: patients within three months of a course of alemtuzumab or cladribine.
- Those who have had haematopoietic stem cell transplantation (follow advice from transplant team).
- Those with bulbar or respiratory failure. This is unusual in people with MS.
- Other inflammatory conditions of the nervous system other than MS (e.g. neuromyelitis optica, cerebral vasculitis, autoimmune encephalitis): risk mainly associated with immunosuppressive therapies.*

Muscle disease (e.g. muscular dystrophies, polymyositis etc): Risk with associated respiratory failure and immunosuppressive therapies.

Neuropathies: risk associated mainly with immunosuppressive therapies for some neuropathies.

Motor Neurone Disease (amyotrophic lateral sclerosis): risk associated with respiratory and bulbar (swallowing/speech) failure.

Neuromuscular junction disorders (e.g. myasthenia gravis, Lambert Eaton syndrome): risk associated with immunosuppressive therapies and bulbar/respiratory failure.

Stroke: risk associated with level of disability/frailty (particularly swallowing problems) and other illnesses.

Dementia: risk associated with level of disability and other illnesses.

Parkinson's Disease and other movement disorders (e.g. ataxia): risk associated with level of disability and other illnesses.

Cerebral Palsy: risk associated with level of disability/frailty (particularly swallowing problems) and other illnesses

Neurological treatments that may increase risk

In addition to the treatments, the presence of additional risk factors may increase overall risk, these include:

- high doses of immunosuppressive drugs
- use of multiple immunosuppressive treatments (past and present).
- active disease
- swallowing or respiratory muscle weakness
- most importantly, the presence of other illnesses such as lung disease (e.g. asthma, chronic obstructive pulmonary disease (COPD), cystic fibrosis and other fibrotic lung diseases), kidney disease, some blood disorders, liver disease, diabetes mellitus, ischaemic heart disease (angina and/or heart attacks), pregnancy and older age/frailty.

- Some patients with very active disease, e.g. newly diagnosed and on IV cyclophosphamide, or who have received antibody depleting therapies, particularly those causing hypogammaglobulinemias (rituximab/ocrelizumab) or alemtuzumab may be at high risk.

* immunosuppressive therapies means any drug that affects the immune system (e.g. prednisolone and other steroids, azathioprine, MMF etc) or other treatments such as immunoglobulin , apheresis or stem cell therapies.

People receiving immune-suppression therapies, put them at higher risk of severe illness from coronavirus (COVID-19) will receive a letter from NHS Scotland outlining more specific advice to keep themselves safe.

The following provides practical guidance on whether you might be in the high risk group or not. The risk to an individual should also take account of other factors such as age and other health conditions. The more risk factors you have (e.g. older age, general ill health, obesity, associated conditions like high blood pressure, heart or lung disease or diabetes), then the greater the risk.

1) **High Risk:** If you:

- are on specific immunosuppressants (e.g. rituximab)
- are on specific immunosuppressants (such as azathioprine, mycophenolate mofetil or mexthotrate) and a daily dose of more than 10mg of prednisolone
- have had haematopoietic stem cell transplantation for Multiple Sclerosis (follow advice from your transplant team)
- have a condition that is affecting your ability to swallow or breath (for example, motor neurone disease, myasthenia stroke and some myopathies)
- are on Multiple Sclerosis therapies such as alemtuzumab or cladribine (especially in last six months).

- 2) **Moderate Risk:** If you:
 - are on a daily dose of between 10-19 mg of prednisolone
 - are on specific immunosuppressants (such as azathioprine, mycophenolate mofetil, mexthotrate, cyclosporine or, apheresis/plasma exchange) and a daily dose of 9mg or less of prednisolone
 - are on Multiple Sclerosis therapies such as fingolimod or ocrelizumab.
- 3) **Low Risk:** If you:
 - are on a daily dose of 9 mg or less of prednisolone
 - are on an intravenous immunoglobulin
 - are on Multiple Sclerosis therapies such as beta interferon, glatiramer acetate, teriflunomide, dimethylfumarate, natalizumab).
- 4) **Normal Risk:** If you are not on immunosuppressant medication. Milder or moderate forms of many of the commoner neurological disorders are not currently considered to confer increased risk, so long as the breathing and swallowing muscles are functioning well and your general health is otherwise good.

If you have questions about this please contact your hospital neurology team and not your GP.

Click this link for [ABN guidance](#) for updated information on how to identify those at high, medium or low risk of complications from coronavirus (COVID-19) infection. This includes condition specific information and how individual immunosuppressant therapies affect risk for people with neurological conditions.

I did not receive a letter from the NHS, but I am currently being treated for a neurological condition, do I need to do anything differently to reduce the risk of Coronavirus?

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 hospital neurology team or your GP.

Should I still go to hospital appointments?

If you are receiving treatment for a neurological condition, it is important that you take extra care of your overall wellbeing, and attending hospital 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 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 neurological condition. Please also inform your clinical team.

Can I have visitors in hospital?

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

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

The symptoms of Coronavirus will be the same as the general population.

NHS Inform Scotland provides up to date advice about coronavirus (COVID-19) <https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19>.

We recommend everyone follows the NHS and Government advice about what to do if they are concerned they have come into contact with someone with confirmed coronavirus.

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 coronavirus (COVID-19) symptoms while you are on your 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.

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 neurological 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 services.

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.

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>

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.

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 neurological 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 neurological 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. For some people with neurological conditions independent handwashing may have additional challenges. Helpful guidance is published here: <https://www.scottishneurological.org.uk/handwashing/>
- 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/>

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 changes [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.