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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 COVID-19 are a new continuous cough 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 at extremely high risk of severe illness with COVID-19. If you are in this group you will receive a letter from NHS Scotland or be contacted by your doctor and should follow shielding measures: <https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19/coronavirus-covid-19-shielding>

What should I know about Coronavirus/COVID-19 and neurological conditions?

Some people with a neurological condition have a higher 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 call for 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).

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.

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

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.

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 alemtuzemab 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 methotrexate) 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, methotrexate, 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.

Identification of people at the highest risk is ongoing, informed by centrally held data and with input from GPs and hospital clinicians. 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 COVID-19 infection. This includes condition specific information and how individual immunosuppressant therapies affect risk for people with neurological conditions.

I am part of the group who are identified as at higher risk of illness and got a letter from the NHS. Is there something I need to do differently to reduce the risk of Coronavirus?

The safest course of action is for you to stay at home at all times and avoid all face-to-face contact for at least twelve weeks, except from carers and healthcare workers who you must see as part of your medical care. The rest of your household should support you to stay safe and closely follow guidance on social distancing, reducing their contact inside and outside the home. This will help protect you by stopping you from coming into contact with the virus.

Things you should be doing to stay safe.

You, or the person you care for, should:

- DO STRICTLY AVOID** contact with anyone who is displaying symptoms of coronavirus (COVID-19). These symptoms include high temperature (above 37.8 °C) and/or a new and continuous cough. You might want to have a thermometer at home to check your temperature if you are worried that you may have a fever.

- DON'T** leave your home.

- DON'T** attend any gatherings. This includes gatherings of friends and families in private spaces e.g. family homes, weddings and religious services.

- DON'T** go out for shopping, leisure or travel. When arranging food or medication deliveries, these should be left at the door to minimise contact.

- DO** keep in touch using remote technology such as phone, internet, and social media.

- DO** use telephone or online services to contact your GP (for non-coronavirus issues) or other essential services.

- DO** regularly wash your hands with soap and water for 20 seconds. Ask carers or support workers who visit your home to do the same. For some people with neurological conditions independent handwashing may have additional challenges. Helpful guidance is published here:

<https://www.scottishneurological.org.uk/handwashing/>

The rest of your household need to support you to stay safe and must stringently follow guidance on social distancing, reducing their contact outside the home.

In your home, you should:

- 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 encourage them to 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 where possible, and 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 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?

If you have not received a letter from NHS Scotland but using this guidance believe you fall within the **highest risk group** you should protect yourself immediately by following the shielding measures 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 not received a letter and do not believe you are in the highest risk group, you do not need to follow shielding measures. If you believe you meet the criteria in this guidance for **moderate or low risk**, you should still be particularly careful in trying to reduce the risk of becoming infected with Coronavirus/ COVID-19. The most up to date guidance for you is to strictly follow social distancing measures:

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

If you meet the criteria set out in this guidance for **normal risk**, then there are no special or different precautions you should take compared to someone without your condition and you should follow social distancing measures:

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

If you are not following shielding measures and 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>.

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. Attending appointments is part of this.

Your neurology team will try to minimise the time you spend in hospital departments and may contact you to change your appointment, 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.

If you have the slightest sign of Coronavirus/COVID-19 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 neurology team.

Being visited by friends or relatives in hospital, or someone going with you to appointments is now 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.

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 and/or a fever/high temperature 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 should ask family, friends and neighbours to support you and use online services.

If this isn't possible, then the public sector, business, charities, and the general public are putting arrangements in place to help those advised to stay at home. It's important to speak to others and ask them to help you to make arrangements for:

- food
- medicines
- essential services and supplies
- looking after your physical health, mental health and wellbeing

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.

As we are being asked to stay at home for a prolonged period, how can I maintain a 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 - 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 can also be found at:

<https://breathingspace.scot/>

<https://www.samh.org.uk/>

<https://www.supportinmindscotland.org.uk/>

Tips on how to cope if you are worried about Coronavirus and in isolation can be found at:

<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>

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

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

You should let your regular visitors know that you are reducing social contacts and they shouldn't visit you during this time, unless they are providing essential care for you. 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. 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>.