

Coronavirus (Covid-19) – Update for People with Ataxia

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What is Coronavirus (Covid-19)

- COVID-19 is a new illness that can affect your lungs and airways. It's caused by a virus called coronavirus.
- The virus is thought to be natural and have an animal origin, through spillover infection.
- Spread via respiratory droplets/ from touching contaminated surfaces and then touching one's face.
- Time from exposure to onset of symptoms is between 2-14 days, with an average of 5 days.
- There is currently no specific treatment for coronavirus.
- Management aims to relieve the symptoms while your body fights the illness.
- While the majority of cases result in mild symptoms, some progress to severe pneumonia and multi-organ failure

What are the symptoms of Covid-19?

- Coronavirus (COVID-19) affects your lungs and airways. Normally, it starts with a fever and dry cough which can lead to a shortness of breath.
- Be alert for the following symptoms:
- a high temperature – over 37.8 degrees. If you don't have a thermometer, check if you feel hot to touch on your chest or back.
- a new, continuous cough – this means coughing repeatedly for a long period.
- If you, or someone you live with, experiences these symptoms follow NHS guidance on how long you should stay at home and self isolate.
- To protect others, do not go to places like a GP surgery, pharmacy or hospital. **Stay at home.**

How long to stay at home

If you have symptoms of coronavirus, you'll need to self-isolate for 7 days. After 7 days:

- If you do not have a high temperature, you do not need to continue to self-isolate
- if you still have a high temperature, keep self-isolating until your temperature returns to normal
- You do not need to self-isolate if you just have a cough after 7 days. A cough can last for several weeks after the infection has gone.
- If you live with someone who has symptoms, you'll need to stay at home for 14 days from the day the first person in the home started having symptoms

- If you live with someone who is 70 or over, has a long-term condition, is pregnant or has a weakened immune system, try to find somewhere else for them to stay for 14 days.
- If you have to stay at home together, try to keep away from each other as much as possible
- **If you feel you cannot cope with your symptoms at home, if your condition gets worse, or your symptoms do not get better after 7 days, then use the NHS 111 online coronavirus service. If you don't have internet access, call NHS 111. For a medical emergency you should dial 999.**

How will Covid-19 affect people with ataxia?

- People with ataxia can experience a temporary worsening in their ataxia symptoms (balance, coordination, vision, speech, etc.) when they are suffering from any infections that cause flu-like symptoms or pneumonia.
- We would expect that if a patient with ataxia develops symptoms from the coronavirus infection, their symptoms of ataxia may get worse while the flu-like symptoms or pneumonia persist.

Are people with Ataxia more at risk of catching Covid-19?

- If you have Ataxia, you have the same risk of developing Covid-19 as anyone else. **There is however special advice for people with autoimmune ataxia, receiving mycophenolate treatment/immunosuppressants**
- The majority of people with Ataxia should be following the governments general advice on **staying at home**. Social distancing is something **everyone** should be following

What is social distancing and what does it mean for people affected by Ataxia?

Social distancing is something **everyone** should be following and includes the requirement to stay at home except for the following four very limited purposes:

- to go to work, if your work is essential and cannot be done from home
- to get food
- to get medicines
- to exercise outdoors, once a day, alone or with members of your household.

If you do leave the house, **stay at least two metres away from other people, and wash your hands carefully when you return home.**

What precautions should I take?

- People with Ataxia are classified as being in the **vulnerable** group because of an **increased risk of complications with Covid-19**
- Everyone who is classed as vulnerable is being advised to follow the stay at home advice particularly stringently. You may well feel that you want to take extra precautions to avoid contact with other people for the time being.
- We recommend following NHS and government precautions, which will be updated regularly:

www.gov.uk/government/publications/covid-19-guidance-on-social-distancing-and-for-vulnerable-people/guidance-on-social-distancing-for-everyone-in-the-uk-and-protecting-older-people-and-vulnerable-adults

Should I have received a letter from the NHS telling me to ‘shield’?

- The NHS has been sending out letters to people who are considered **extremely vulnerable** and at very high risk of severe illness from coronavirus Covid-19.
- People who've received one of these letters have been advised to **shield**. This means staying at home at all times and avoiding all face-to-face contact for at least twelve weeks from the day you receive the letter. The only exception to this is contact with carers and healthcare workers who you must see as part of your medical care.

‘Extremely vulnerable’ people advised to shield include:

- Solid organ transplant recipients
- Some people with cancer who are undergoing treatments such as chemotherapy and radiotherapy
- People on immunosuppression drugs
- Women who are pregnant and have heart disease
- People with severe respiratory conditions - cystic fibrosis, severe asthma and COPD
- Some people with rare diseases such as severe combined immunodeficiency

The Association of British Neurologists (ABN) recommend that people with neurological conditions plus additional health problems should be included on this list

‘Extremely vulnerable’ people with ataxia include:

- If you are **over 70 years of age** with ataxia
- Ataxia with any **additional comorbidities** including: diabetes, cardiac complications such as cardiomyopathy, or respiratory complications
- Ataxia with **significantly reduced mobility** i.e. wheelchair bound or living in a care home
- Ataxia with **significant difficulties swallowing**
- Ataxia taking **immunosuppressants** for comorbidities or autoimmune ataxia
- Ataxia with **pregnancy plus** underlying cardiac complications

Pregnancy and Covid-19

- Pregnancy in a small proportion of women can alter how your body handles severe viral infections, and for this reason pregnant women have been placed in the 'vulnerable' category.
- This is something that midwives and obstetricians have known for many years and are used to dealing with. As yet, there is no evidence that pregnant women who get this infection are more at risk of serious complications than any other healthy individuals.
- If you are in your third trimester (more than 28 weeks pregnant) you should be particularly attentive to social distancing and minimising contact with others.
- Pregnant women with cardiac complications are considered to be in the 'extremely vulnerable' category, and are likely to be advised to shield for 12 weeks
- All pregnant women should follow the PHE advice: Guidance on social distancing for all vulnerable people including pregnant women

What should I do if I've received a letter?

- You are strongly advised to follow the government's guidance on shielding and protecting extremely vulnerable people
- All people who have been told to shield should register on the government website (<https://www.gov.uk/coronavirus-extremely-vulnerable>) to let them know whether or not you need support. This will help you access support with food and medication deliveries.
- Even if you don't need any support with daily tasks, you should still register to let the government know.

What if I haven't received a letter when I think I should have?

- The NHS has sent out letters to the majority of people who should be shielding. However there may be a very small number of people who've been missed off this list. GPs and specialists have been asked to review their patient records to identify anyone who they consider to be extremely vulnerable but wasn't sent a letter.
- Identifying who is extremely vulnerable is an ongoing process and letters will be sent out to anyone who has been missed.
- It is important for you to contact your GP if you think you fall into this category and haven't received a letter. **You can still register on the government site for additional support even if you have not yet received the letter.**

NB: for the registration to go through, respondents need to click 'yes' on the page '*Do you have a medical condition that makes you extremely vulnerable to coronavirus?*' (if you click 'no' it states that you are ineligible).

Should I shield if I haven't received a letter?

- Even if you haven't received a letter, you can still choose to shield. This will be a personal decision
- If you haven't been advised to shield by a health professional, you may not be eligible for government support (eg. food and medicine delivery services). If this makes it difficult for you to shield, try to follow the social distancing guidance as closely as you can. Alternatively, you may be able to get support from your local mutual aid group (<https://covidmutualaid.org/>)
- For more information about what shielding involves, read the government's guidance on shielding and protecting extremely vulnerable people.

<https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19>

I live with someone with Ataxia - what should I do?

If you are caring for someone with Ataxia, there are some simple steps that you can take to protect them and to reduce their risk at the current time. Ensure you follow advice on good hygiene such as:

- Wash your hands often, using 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 afterwards.
- General interventions may include increased cleaning activity and keeping property properly ventilated by opening windows whenever safe and appropriate

- The government does not **currently** recommend the use of facemasks as an effective means of preventing the spread of infection. Facemasks play an important role in clinical settings, such as hospitals, but there's very little evidence of benefit from their use outside of these settings. (PHE Guidance as updated 9th April 2020)
- If the person with ataxia needs to go to hospital due to Covid-19, we suggest taking the following:
 - A statement saying that you have ataxia, e.g. a copy of your latest clinic letter
 - Any additional care needs you require (e.g. help with mobility or personal care)
 - A list of any medication you are taking, including dose and frequency
 - Neurologist details, and details for any other specialists involved in your care e.g. cardiologist, respiratory specialist
 - If you have an advanced care plan, please include that.

Covid-19 and mental wellbeing

- Many of us are worried by the impact that coronavirus is having on the lives of ourselves and our families. Being asked to stay at home and avoid other people can make it feel more difficult than usual to take care of mental health and wellbeing.
- Mind has some suggestions of ways to help us all cope
<https://www.mind.org.uk/information-support/coronavirus/coronavirus-and-your-wellbeing/#TakeCareOfYourMentalHealthAndWellbeing>
 Includes ways to connect with other people, through phone calls or social media; planning how you are going to spend your time; finding ways to relax and be creative; ways to keep your mind stimulated.
- The NHS also offer the below advice on mental wellbeing:
 10 tips to help if you are worried about coronavirus
<https://www.nhs.uk/oneyou/every-mind-matters/coronavirus-covid-19-anxiety-tips/>
 Mental wellbeing while staying at home
<https://www.nhs.uk/oneyou/every-mind-matters/coronavirus-covid-19-staying-at-home-tips/>

Covid-19 and physical wellbeing

- It is important for people with ataxia to remain as active as possible within the restraints of social distancing
- If you have a home exercise program provided by a physiotherapist try to perform your exercises daily
- Exercise that focuses on core stability and balance such as Pilates or yoga is particularly important. Below are NHS links to simple floor and chair based Pilates exercises you can do at home:
- <https://www.nhs.uk/conditions/nhs-fitness-studio/pilates-for-beginners/>
- <https://www.nhs.uk/conditions/nhs-fitness-studio/chair-based-pilates-exercise-video/>

Staying up to date on coronavirus around the UK

- The UK Chief Medical Officers have raised the risk to the public from moderate to **high**, at the time of writing.
- Current information and guidance for the UK can be found:
- **England** - follow advice from the [NHS](#) and [Government](#)
- **Scotland** - follow advice from [NHS Inform](#) and [Government](#)
- **Wales** - follow advice from [Public Health Wales](#) and [Government](#)
- **Northern Ireland** - follow advice from [Public Health Agency](#)
- These sources reflect the most up to date information and will be updated as the situation progresses.

Finding local support

Whatever your situation might be, if you need help with something practical (for example getting food shopping or medication) you can find local voluntary services on:

<https://www.ncvo.org.uk/ncvo-volunteering/find-a-volunteer-centre>

<https://covidmutualaid.org/>

Search on both sites using your post code to find local volunteers.



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Contact Helpline: 0845 644 0606

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Covid-19

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If you need help with this contact the Ataxia UK helpline on 0845 644 0606, Mon-Thurs, 10.30-14.30, or e-mail help@ataxia.org.uk.