

ATAXIA

Ataxia UK Annual Conference
16th-17th October 2020

Coping with Covid-19 What do people with Ataxia do now?

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Your risk from Covid-19 if you have Ataxia

Public Health England has identified the main factors that increase the risk of becoming seriously ill with coronavirus as:

- being older
- being a man
- being obese (with a BMI over 30)
- your ethnic background
- **having an underlying health condition (including ataxia)**
- a weakened immune system

Everyone is different, and your own level of risk is affected by many different interacting factors

Public Health England may update this guidance if the scientific advice or spread of coronavirus changes.



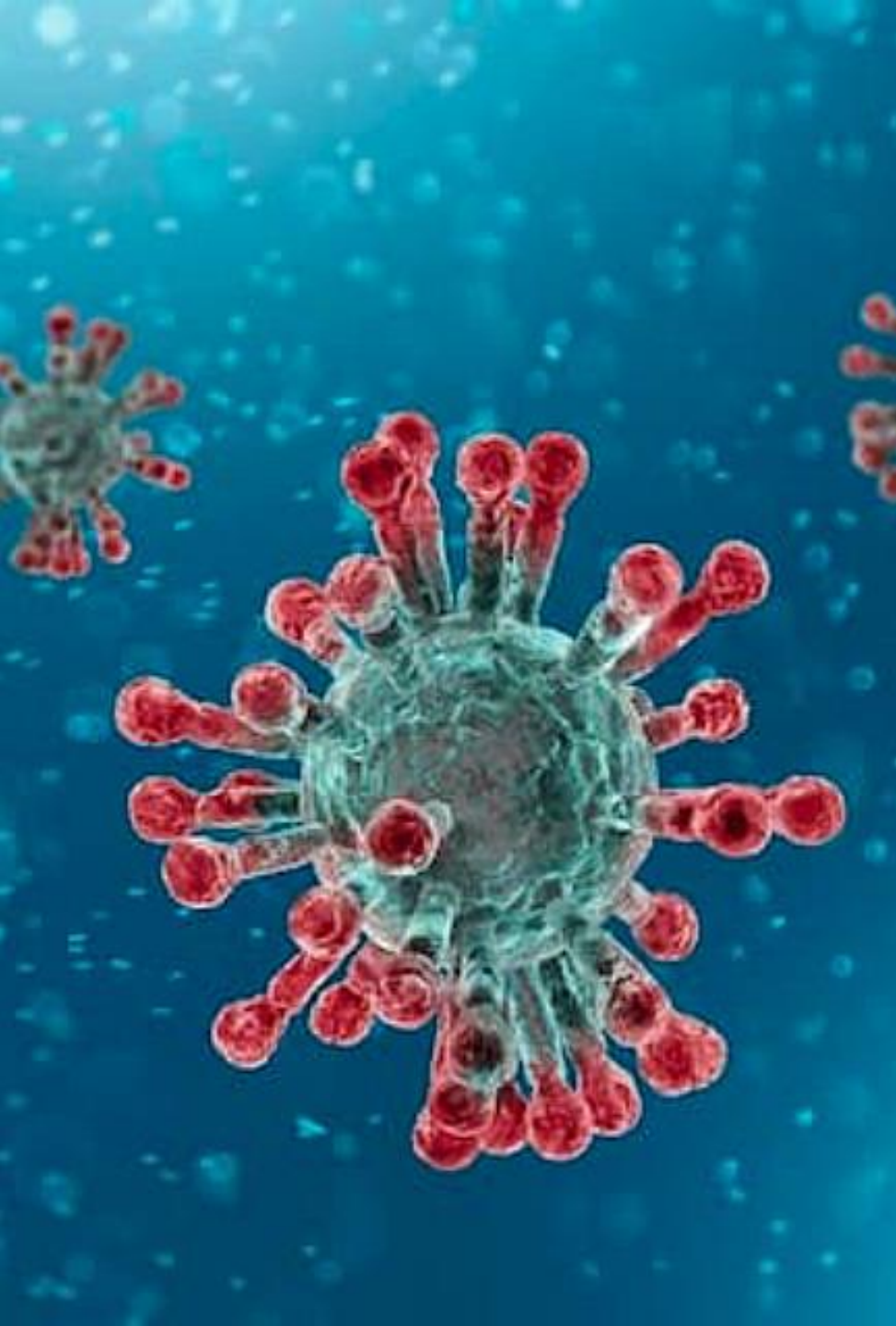
'Extremely vulnerable' people with ataxia

- 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** cardiac complications



Shielding measures for people who are extremely vulnerable

- Strict shielding measures for people in the UK classed as **extremely vulnerable** were introduced in March.
- **You will have been contacted by the NHS if you fall into this category.**
- Shielding was **paused in August** due to lowering rates of transmission
- Unlike in March, there are **other protective measures in place** - rule of six and the wearing of face coverings - to help reduce the spread.
- Your name will be kept securely on the shielded patient list by NHS Digital.
- **You may be advised to shield again** as the situation changes and there is an increase in the transmission of COVID-19 in the community.



How will Covid-19 affect people with ataxia?

- Not more likely to catch Covid-19
- Temporary worsening of ataxia symptoms (balance, coordination, vision, speech, etc.) with **any infections**
- We would expect that if a patient with ataxia develops symptoms from Covid-19, their **symptoms of ataxia may get worse** while the flu-like symptoms or pneumonia persist
- **Covid-19 and Ataxia Survey** and **CoroNerve Studies Group**

How to reduce your risk of catching COVID-19



Keeping	your distance from anyone outside your household
Washing	your hands often, using soap and warm water, or hand sanitiser
Avoiding	crowded places and not meeting up with large groups of people – either indoors or outdoors
Wearing	a face covering, if you can wear one
Following	this advice is especially important if you are vulnerable.

Face masks/coverings

When used correctly, will reduce the spread of coronavirus droplets, helping to protect others. **A face covering should:**

- **cover your nose and mouth** while allowing you to breathe comfortably
- **fit comfortably but securely** against the side of the face
- be **secured to the head** with ties or ear loops
- be made of a material that you find to be **comfortable and breathable**, such as cotton
- ideally include **at least two layers of fabric** (WHO recommends three depending on the fabric used)
- unless disposable, it **should be able to be washed** with other items of laundry according to fabric washing instructions and dried without causing the face covering to be damaged
- It's a good idea to have more than one face covering for each journey so that you can **replace it when it begins to get damp.**
- **Wash hands** thoroughly with soap and water for 20 seconds or use hand sanitiser **before applying mask, before removing, and after removing mask.**

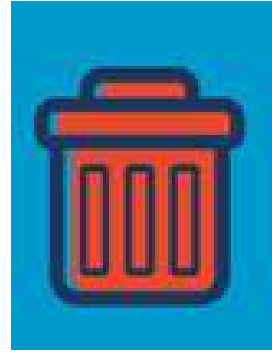


You do not need to wear a face covering if you have a health problem or disability that means you cannot put on, wear or remove a face covering.

- You do not have to provide medical evidence of your reason for not wearing a face covering, but you may wish to carry a face covering exempt card.

You can [order one from Hidden Disabilities](#) for a small charge

- Advice on how to prevent glasses steaming up: <https://www.specsavers.co.uk/covid19-care/stop-glasses-fogging-with-face-mask>



Physical distancing, hand hygiene and respiratory hygiene are still the most important and effective things we can all do to prevent the spread of coronavirus.



The wearing of face coverings must not be used as an alternative to any of these other precautions.



Making decisions about what to do

visit family
or friends

go out for
dinner

use public
transport

go back
into your
workplace.



Personal attitude to risk

- How much would you benefit from going somewhere?
- How much you could potentially be exposed to coronavirus?
- Will you be inside or outside?
- How many people will be there?
- Will there be many people you don't usually meet?
- How big is the space?
- What are the bathroom arrangements?
- It's ok to say no

Know the level of risk in your area: Local Covid Alert Levels



[Home](#) > [Coronavirus \(COVID-19\)](#)

Find out the coronavirus restrictions in a local area

There are different restrictions in [Scotland](#), [Wales](#) and [Northern Ireland](#)

Enter the postcode of the place you want to find information about. For example where you live, work, or visit.

Each area has a [Local COVID Alert Level](#). There are 3 Local COVID Alert Levels. Sometimes this is known as a 'local lockdown'.

You can find out what you can or cannot do.

Enter your postcode

For example SW1A 2AA

Find

[Find a postcode on Royal Mail's postcode finder](#)

- High rates of infection in your area = higher risk of exposure
- <https://www.gov.uk/guidance/local-covid-alert-levels-what-you-need-to-know>
- <https://www.gov.uk/find-coronavirus-local-restrictions>


 Llywodraeth Cymru
 Welsh Government
 Cymraeg

» Follow the [advice for coronavirus \(COVID-19\)](#) and [local coronavirus re](#)

[Home](#) > [Coronavirus \(COVID-19\)](#) > Local lockdown



SUB-TOPIC

Local lockdown

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Restrictions to reduce the spread of coronavirus and protect public health in Bangor



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CORONAVIRUS (COVID-19)

Coronavirus (COVID-19): regulations and localised restrictions

Following an increase in coronavirus (COVID-19) cases, additional restrictions have been introduced for people living in certain areas. These are aimed at limiting the chances for the virus to spread between households. This page contains information on what you can and cannot do if you live in an affected area.

Areas with local restrictions

The NI Executive announced on 1 October 2020 that additional restrictions were being introduced for people living in the **Derry City and Strabane District Council area**.


 Scottish Government
 Rìghaltagas na h-Alba
 gov.scot

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Coronavirus in Scotland

i Further temporary measures to stop the spread of coronavirus will come into effect from Friday 9 October. This includes additional restrictions for central belt areas. [Read more about the new measures.](#)

Different Restrictions in Scotland, Wales and NI

New Three-Tier Covid Alert System: **Medium**, High, and Very High Alert Levels

Tier 1: Medium alert level:

- Strictly observe social distancing
- Meet others **outside** where possible
- Limit unnecessary journeys on public transport
- Work from home where possible
- People can still go to work and children should still attend school.
- **Rule of six applies indoors/outdoors** $\Delta \perp \Delta$
- **Masks** (indoor settings: shops, transport, hospitality-except when eating/drinking) $\Delta \perp \Delta$

Additional Advice for Extremely Vulnerable People:

- Try to keep the number of different people you meet low. The fewer people you meet, the less likely you are to catch COVID-19.
- You do not need to maintain social distancing with members of your own household.
- If you cannot work from home, you can still attend your workplace if COVID-secure.
- Consider shopping or visiting the pharmacy at quieter times of the day.

New Three-Tier Covid Alert System: Medium, High, and Very High Alert Levels

Tier 2: High alert level:

- Reduce the number of different people you meet outside
- Avoid travel except for essential journeys
- Work from home where possible
- Reduce the number of shopping trips made
- Going to work - in Covid-secure workplaces - permitted if cannot work from home
- Children should still attend school
- **No mixing with other households indoors**, unless part of a support bubble apply as does the rule to meet in **groups of no more than six outdoors** $\Delta \updownarrow \Delta$
- **Masks** (indoor settings: shops, transport, hospitality-except when eating/drinking) $\Delta \updownarrow \Delta$



Additional Advice for Extremely Vulnerable People:

- Continue to go outside with your household and/or support bubble because of the benefits of exercise.
- Children should still attend school (unless one of the very small number of pupils or students under paediatric care that have been advised by GP/clinician not to attend an education setting).
- Travelling in a private car with your own household or bubble lower risk than public transport
- Reduce the number of shopping trips you make and at quieter times of the day.
- Consider using online delivery/ask friends and family to help

New Three-Tier Covid Alert System:

Medium, High, and
Very High Alert Levels

Tier 3: Very high alert level:

- Work from home and stay at home as much as possible
- Avoid all but essential travel
- Reduce shopping trips, and if possible use online delivery
- People in these areas are encouraged to still go outside for exercise, and can still go to school and to work if they cannot work from home
- Additional support should be available from local authorities
- **No mixing with other households indoors**, unless part of a support bubble apply as does the rule to meet in **groups of no more than six outdoors** 
- **Masks** (indoor settings: shops, transport, hospitality-except when eating/drinking) 

Additional Advice for Clinically Extremely Vulnerable People:

- Continue to go outside for exercise, but avoid busy areas
- You may want to maintain social distance within your household if practical.
- **Strongly** advised to work from home
- If there is no alternative, you can still go to work if **Covid-secure**
- If you have concerns about your health and safety at work you can raise them with your workplace union, the [Health and Safety Executive](#) or your local authority.
- **Significantly reduce shopping trips** and consider shopping online/shop at quieter times

New Three-Tier Covid Alert System

Shielding:

Shielding advice may be reintroduced in the future in **hotspot areas** in exceptional circumstances based on advice from the Chief Medical Officer.

If that happens, people in the shielding category **may again be advised to stay at home, not go to work or school** and **limit social interactions** to their own household and support bubble.

Shielding will not automatically be triggered by an area going into tier three (Very High Alert Level).

Different Restrictions in Scotland, Wales and NI

Wales

- Rule of 6 doesn't include children under the age of 11
- If you meet another household, outside your extended household, stay outdoors
- CMO will communicate via local radio and television and if shielding is necessary he will write to you again.
- [Advice on shielding in Wales](#)

Scotland

- Restrictions on not meeting other households indoors, unless part of a support bubble
- You can meet people outside, in your garden or a public space, in groups of up to 6 people from no more than 2 households (not counting under-12s).
- If the Scottish Government see an increase in infection rates that gives them concern, they may ask you to take extra steps again to stay safe. If so, they'll let you know by letter and through the SMS Shielding Service.
- [Advice on shielding in Scotland](#)

Northern Ireland:

- Restrictions on not meeting other households indoors, unless part of a support bubble
- No more than six people to gather in a private garden from no more than two households - children aged 12 and under from those two households are not counted in this total
- Schools will close from Monday
- [Advice on shielding in Northern Ireland](#)



How can I protect myself if I can't work from home?

- Think of how you're getting to and from work
- Try to avoid peak times.
- Changing your working hours/shift pattern
- Carry hand sanitiser for journey
- Changing rotas so that you're with the same people each time
- working in smaller teams
- **You should only be going back to work if your workplace is COVID-secure** (risk assessment, social distancing, cleaning, hygiene and handwashing)



Caring for someone extremely vulnerable – what can I do?

There are some simple steps that you can take to protect them and reduce their risk.

- Work from home if you can.
- Limit contact with other people.
- Keep your distance if you go out (2 metres apart where possible/ mask if not possible).
- Wash your hands and clothes regularly.
- Self-isolate if you, or anyone, in your household has symptoms
- Any carers or visitors who support you with your everyday needs can continue to visit.
- Visit the [Guidance for those who provide unpaid care to friends or family](#).
- Find out about different sources of support that could be used and access further advice on [creating a contingency plan available from Carers UK](#).

Reducing anxiety



- **Control what can be controlled** - before leaving your home, plan how you'll stay safe and minimise the risk of spreading the virus.
 - whether and how you'll avoid touching surfaces that others have touched
 - how you'll practice good hygiene
 - where physical distancing might be more difficult to follow, and how you'll avoid or reduce the risk
 - what additional things you may need to take with you, such as hand sanitiser, a bag for used tissues and a face covering
- **Look after your wellbeing** - Finding routines, staying connected, eating well, and taking exercise apply just as much now as they did at the start of lockdown – arguably even more so as we remain in a period of high stress but with more demands on us.
- **Limiting media exposure** to a few trusted sources
- Focus on the **positives** and focus on the **present**

Covid-19 and Mental Wellbeing

If you are struggling with your mental health, **it is ok to ask for help**. A good place to start is by speaking to a friend or your GP.

Here are a few organisations that can help you look after your mental health:

- [Every Mind Matters](#)
- [Clear Your Head \(Scotland\)](#)
- [Rethink](#)
- [Mind](#)
- [Mental Health Foundation](#)



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/>
- **Minimise Covid risks** e.g. reduce excess weight, increase cardiovascular fitness, ensure optimum management of underlying health problems, flu vaccine, limit alcohol, stop smoking.

Information and Support



- **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 [NI Direct](#)
- **NHS support:**

Even if you're not in the shielding group, if you meet certain criteria (people with ataxia are eligible) you can access support from the NHS volunteer responders.

Help with shopping, getting prescriptions or just checking in to see how you are doing.

You can [request this support online](#) or by calling 0808 196 3646

Last updated on 15/10/2020

Covid-19 and ataxia survey

(For people with ataxia that had or believe they had Covid-19).

Ataxia UK's medical advisors hope to learn more about the impact of Covid-19 on people with ataxia.

Can be
found on
our
website



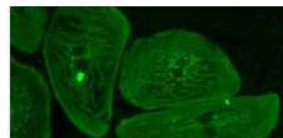
For people with cerebellar ataxia



Healthcare research



Brain donation



For people with Friedreich's ataxia



For people with ataxia of unknown cause



ATAxia

ANY QUESTIONS?

