

Thank you to everyone who joined the Alström virtual get together on Friday 8th January 2021. I hope we answered some of your questions and concerns. Don’t worry if you missed this one, we have brought together the information for you.

As you know, the pandemic is changing daily and we all have more questions than answers, but we have brought together some top tips from the webinar which we hope will help.

**Adults diagnosed with Alström Syndrome remain clinically extremely vulnerable and should be shielding and taking precautions.**

From 5th January 2021 new national restrictions begin:

* Stay at home except for attending medical appointments and to exercise once a day.
* Avoid meeting anyone you don’t live with except if they are in your support bubble.

**Leaving home**

You must not leave or be outside of your home except where necessary.

**Shops and Pharmacies**   
Try to get someone to collect your shopping/medicines for you or use online services. The NHS Volunteer Service may be able to help with this [**https://nhsvolunteerresponders.org.uk/**](https://nhsvolunteerresponders.org.uk/)

**Exercise**   
Only with your household (or support bubble), this should be limited to once per day, and you should not travel outside your local area.

**Medical Assistance**  
It is important to seek medical assistance when needed to avoid injury, illness or risk of harm (including domestic abuse).

**Remember Hand. Face. Space**

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**Hands** – wash your hands regularly and for at least 20 seconds.

**Face** – wear a face covering in indoor settings where social distancing may be difficult, and where you will come into contact with people you do not normally meet.

**Space** – stay 2 metres apart from people you do not live with where possible, or 1 metre with extra precautions in place (such as wearing face coverings).

**Government Guidance**

Keep up to date with the latest guidance on the individual Government websites:

**England**

[**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**](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)

**Wales**[**https://gov.wales/guidance-shielding-and-protecting-people-defined-medical-grounds-extremely-vulnerable-coronavirus-0**](https://gov.wales/guidance-shielding-and-protecting-people-defined-medical-grounds-extremely-vulnerable-coronavirus-0)

**Scotland**[**https://www.gov.scot/publications/covid-shielding/**](https://www.gov.scot/publications/covid-shielding/)

**Northern Ireland**[**https://www.nidirect.gov.uk/articles/guidance-shielding-extremely-vulnerable-people**](https://www.nidirect.gov.uk/articles/guidance-shielding-extremely-vulnerable-people)

**Vitamin D**

FREE 4-month supply of vitamin D supplements for all adults who are clinically extremely vulnerable to support general health.

During autumn and winter, everyone is advised to take vitamin D to keep their bones and muscles healthy and to support their general health.

This is particularly important if you've been indoors over the spring and summer as you may not have been getting enough vitamin D from sunlight.

Dr Tarek Hiwot recommends that adult patients should have 800 units of vitamin D daily.

**Apply** [**https://www.nhs.uk/get-vitamin-d**](https://www.nhs.uk/get-vitamin-d)

**We hope this date will be extended as the recent shielding letters indicated, but currently you need to apply before Monday 11 January 2021**

Further guidance on how to safely take vitamin D supplements will be provided during the opt in process.

You can also find out more about vitamin D on the NHS website  
[**https://www.nhs.uk/news/food-and-diet/the-new-guidelines-on-vitamin-d-what-you-need-to-know/**](https://www.nhs.uk/news/food-and-diet/the-new-guidelines-on-vitamin-d-what-you-need-to-know/)

**Questions from families**

**Q1. Can we still gain additional services, such as priority shopping slots?**

Yes, all those who are extremely clinically vulnerable should receive these services if needed.

If you haven’t already registered for priority shopping and support services, then please follow the link to the Gov.uk website.

**You can add or update your details on the Gov.uk website** [**https://www.gov.uk/coronavirus-shielding-support**](https://www.gov.uk/coronavirus-shielding-support)

If you need help to collect shopping:

**The NHS Volunteer Service may be able to help with this** [**https://nhsvolunteerresponders.org.uk/**](https://nhsvolunteerresponders.org.uk/)

**Q2. Can we form a support bubble with another household?**

The guidance states that those who are clinically extremely vulnerable can form a support bubble with another household. It is still very important that you don’t mix with others outside your household and remain within this one support bubble if needed.

You can still receive care at home from social care and medical professionals. Any carers, PA’s or visitors who support you with your needs can continue to visit.

**Q3. What precautions can we take to stay safe?**

People with Alström are in the clinically extremely vulnerable category and must take this pandemic seriously. Remember to stay at home, have others collect your shopping and prescriptions for you and remember hand, space, face. This includes if you have carers coming into your home, to wear a face mask to stay safe.

**Q4. Are people with AS still on the shielding list?**

Yes, adults affected by AS will remain on the shielding list.  
You should have all received your shielding letter, if you haven’t received your letter by the 15th January 2021, please let us know so we can look into this for you.

**Q5. Are people with AS classed as extremely vulnerable?**

Yes, adults with AS are classed as clinically extremely vulnerable and should be staying at home.

**Q6. What are the early signs of Covid?**

* New and continuous cough
* High temperature
* Loss of taste and/or smell

**Q7. When should we seek further medical support?**

* If you become breathless seek medical assistance
* If you are concerned about your health in any way dial 111 for guidance or in an emergency call 999
* Contact ASUK if you receive a positive Covid-19 test result, we can then inform the AS clinical team

**Remember:**

* **Call 111 if you have symptoms**
* **Call 999 if shortness of breath occurs.**

**Q8. What do I do, if someone in my household gets Covid?**

* Book a Covid-19 test for yourself to see if you have Covid
* Self-isolate

**Self-isolation** is what you should be doing if you get coronavirus yourself. You need to remove yourself to a room, away from everyone else in the family and stay there for 7 days. If you are fortunate to have more than one bathroom then have one bathroom for yourself and one bathroom for everyone else. Whilst you are in the room, people should bring your food up on a tray and leave it outside your door.

**Q9. When are people with AS likely to receive the vaccine?**

The Government has advised that clinically extremely vulnerable people are in priority group 4 and should have received the vaccine by mid-February.

**Q10. When are carers likely to receive the vaccine?**

Those who receive carers allowance or those who are main areas of an elderly or disabled person, are now in priority group 6 and they too should have received their vaccine by mid-February.

**Q11. Is the vaccine something you would recommend for AS patients?**

Yes, both the AstraZeneca and Pfizer vaccines available are very similar and you should have whichever one is offered to you. Covid-19 is very serious, and the vaccine is the only known way to try and protect ourselves.

**Q12.**

**What side effects should we be aware of?**

As with all vaccines, there are side effects which people have reported these include:

* General aches or flu like symptoms
* Sore, achy arm from where the vaccine was given
* Tiredness
* Headache

**Q13. Does the vaccine contain any animal products?**

The 2 approved COVID-19 vaccines do not contain any animal products or egg.

**Q14. What is your advice for people with allergies?**

Tell healthcare staff before you are vaccinated if you've ever had a serious allergic reaction (anaphylaxis).

You should not have the vaccine if you've ever had a serious allergic reaction to:

* a previous vaccine
* a previous dose of the same COVID-19 vaccine
* some medicines, household products or cosmetics

Serious allergic reactions are rare. If you do have a reaction to the vaccine, it usually happens in minutes. Staff giving the vaccine are trained to deal with allergic reactions and treat them immediately.

**Q15. Do other people in the household need to shield too?**

Those living in the same house as a person who is shielding should continue to follow the guidance for the general public. They should work from home if they can, but if not, they are advised to continue going to work.

**Important points to remember:**

* **Call 111 if you have symptoms and would like advice**
* **Call 999 if shortness of breath occurs**
* All those affected by **Alström Syndrome should stay at home**
* Provisions should be brought to you
* Remember hand, face, space

**Where to find further resources**

You can find a range of resources on our website; including the latest guidance about coronavirus, where to find support and how to stay connected and entertained whilst at home [**http://www.alstrom.org.uk/family-support/**](http://www.alstrom.org.uk/family-support/)**.**  
Please get in touch with Catherine Lewis, her email address is [Catherine.lewis@alstrom.org.uk](mailto:Catherine.lewis@alstrom.org.uk) if there are specific services which you think would be helpful for other families to know about and we can add these to our resource section.

**Keep in touch**

ASUK are here for you, we are open and feel free to contact your family support worker if you need any support. We can call you, you can call us.

A person posing for the camera

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A person smiling for the camera

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Best wishes

  
Ann Chivers and the ASUK Team