

Thank you to everyone who joined the Alström virtual get together on Friday 27th March 2020. I hope we answered some of your questions and concerns. Don’t worry if you missed this one, we are planning on these becoming a regular fixture for all to get together to discuss a range of topics.

As you know, the epidemic 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.

We have also attached the transcript from the webinar if you would like the full answers to the questions below:

**Are children and adults diagnosed with Alström Syndrome (AS) classed as ‘extremely vulnerable’?**

The guidance has recently changed and both children and adults with AS are now classed as extremely vulnerable.

The clinical teams from the Queen Elizabeth Hospital and Birmingham Children’s Hospitals are currently issuing letters to all families affected by Alström Syndrome.

**What does ‘shielding’, ‘social distancing’ and ‘self-isolation’ mean?**

**Shielding** is what you should do if you have AS, it is a way to protect yourself and your family. This guide is for all members of your household

* DO NOT leave the house
* DO NOT go out to get shopping, including medicines
* DO NOT go out for exercise, including walking the dog

**Social distancing** is what you should be doing if you live in the same house as someone with AS. It means staying at home, working at home, avoiding meeting up with other people, keeping at least 2 metres apart from other people, only going out for essentials, such as food, medicines or once a day to exercise.

**Self-isolation** is what you should be doing if you get coronavirus yourself, not someone with AS. 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.

**Is it safe for other members of the household to still go out?**

Other members of the household can still go out into the community if they are:

1. Buying essentials such as food
2. Getting medicines
3. Exercising, this can be once a day, that includes walking the dog
4. Follow social distancing guidance

**What should patients do if they have the symptoms and feel they need medical attention?**

1. Call the 111 service or your GP

2. Contact your local teams such as paediatrics to see what advice they can provide

DO NOT walk into a GP practice, Hospital or A&E department

**Remember:**

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

**I am concerned about medication, what is the guidance?**

There is no national shortage of drugs for the NHS, there is plenty of what is needed.

**Top Tips:**

* Continue with your medication, as stopping any medication could cause more problems
* You should continue to get your supplies from your local pharmacy
* Order your prescriptions in good time
* You should be able to order online or by telephone
* Call your pharmacist first to check your medication is there and ready
* Your family member should get these for you or have them delivered to you

**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
* You can go out into your own garden, but no further
* If you have a dog, someone should walk them for you

**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