



# Alström Syndrome UK

Strength for today, hope for the future

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## Guidance for Alström families in Corona virus epidemic

### Background

1. People affected by Alström Syndrome are known to be at risk of severe illness when they develop chest infections.
2. This includes seasonal influenza and community acquired pneumonia, for which ASUK and the Birmingham clinics have advised annual influenza vaccination and 5 yearly pneumococcal (pneumonia immunisation).
3. There is reason for cautious optimism that this is effective from the improved health of our Alström families.
4. Corona virus is a new “flu like” infection which causes a milder illness or even goes unnoticed in many people. However, in people with background heart or lung problems or diabetes the infection can progress after 7 days to severe life-threatening pneumonia, rather than resolving.
5. At the danger time:
  - The person’s immune response “Kicks in” (work published in Nature from New Zealand). This marks recovery but can cause fluid in the lungs.
  - Other germs may infect the lungs as may occur in standard “flu”.
  - If not cleared properly the virus itself may spread throughout the lungs.

**Any one of or a combination of these factors can be life threatening**

### Treatment in severe cases

With serious progression of the illness outlined above patients are admitted to hospital for fluids into the veins, oxygen and antibiotics. If their lungs continue to be too wet to absorb enough oxygen, then going on to a breathing machine will be necessary.

## **When to call for help**

1. Scrupulously follow isolation for all the family with immediate effect
2. If non Alström family member develop symptoms they should strictly isolate/quarantine themselves as given in NHS England advice.
3. Be cautious with a combination of 1) prolonged fever-cough and 2) shortness of breath (the latter since the first day). Assume Corona virus infection and telephone call to GP to highlight that a vulnerable patient potentially has the condition.
4. If breathlessness becomes severe or there is any clouding of consciousness/confusion, phone 999; once admitted, ask permission to involve Tarek, Tim or team to liaise with admitting hospital team.

The Alström Syndrome clinical lead contact numbers are:

### **Dr. Tarekegn Hiwot (adult services)**

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### **Prof Tim Barrett (children's services)**

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With thanks to the Alström Syndrome clinical team  
for producing this guidance for families.

ASUK is here to support you.