

Alström Syndrome Telemedicine Clinics
Queen Elizabeth Hospital, Birmingham

What is a Telemedicine Clinic?

A Telemedicine Clinic is a way of using technology to deliver healthcare at a distance to patients and their families.

How will I be invited to take part in a Telemedicine Clinic?

The hospital will send you a letter or email confirming the date and time of your appointment which will include a link to join your Telemedicine appointment on VidyoConnect.

What is VidyoConnect?

VidyoConnect allows patients and healthcare providers to meet virtually by using a computer or mobile device. You can download VidyoConnect from the App Store or Google Play Store. It is free and quick to install.

Who will be taking part in the Telemedicine Clinic?

Dr Tarek Hiwot or Dr Charlotte Dawson will lead the Telemedicine Clinic and be joined by other members of the Alström team. This may include Dr Rick Steeds - Cardiologist, Dr Shyam Madathil – Respiratory Specialist, Antonio Ochoa-Ferraro – Pharmacist, Sarah Steeds or Helen Gallagher - Nurse Specialists, Sarah Howe - Dietician, Nicola Condon – Physiotherapist and Anne-Marie Walker – Psychologist.

How can I prepare for the Telemedicine Clinic?

There are a few things you can do to help you prepare:

- Before your appointment, you will be sent a home blood sample kit in the post. Please collect your blood sample as soon as possible and return it in the envelope provided. Here is a link to instructions about how to do your blood sample <https://www.exeterlaboratory.com/instructions/>
- Use your home monitoring equipment and make a note of your weight, waist circumference and blood pressure. Here is a link to information about how to use the equipment <http://www.alstrom.org.uk/nhs-clinics/>
- Download VidyoConnect to your computer or mobile device
- Make sure your device has a camera, microphone and speakers (mobile devices and laptops often have these built in)
- Put together a list of your medications and make a note of any changes since your last Alström Syndrome clinic appointment

- Make a note of any new health professionals involved in your care
- Make a note of any questions or concerns you may have
- Complete the food diary if one has been sent to you by the Dietitian
- Decide if you would like anyone with you during the Telemedicine Clinic, bearing in mind any local restrictions in place due to the pandemic
- Find somewhere quiet in your home. Turn off radios or TV to minimise any background noise.

How will the Telemedicine Clinic work?

On the day of your appointment you will be sent an email with a Vidyo link. Please check your junk folder in case the email goes in there. Please click on the link provided in the email and follow the instructions to join. You are free to join any time before the start of your appointment. You will be placed in a waiting room and then at the time of your appointment or shortly after, you will be taken to a different screen where Tarek and the team will appear.

Please do not worry if you have any technical issues. If you do not appear on screen, then Tarek will contact you by telephone.

What happens after the Telemedicine Clinic?

You will receive a clinic summary letter in the post and a copy will also be sent to your GP and other health professionals involved in your care.

What if I have further questions after the Telemedicine Clinic?

You can contact your Family Support Worker at Alström Syndrome UK:



Jane Biglin
 Senior Family Support Worker
 (for patients living in the South of England)
 Email: jane.biglin@alstrom.org.uk
 Telephone: 07714 798413



Carrol Birchall
 Senior Family Support Worker
 (for patients living in the Midlands & North of England)
 Email: carrol.birchall@alstrom.org.uk
 Telephone: 07847 760467