Nurse-led Aortopathy Clinic

Where is the clinic?

The clinic will be in the main Outpatient building at the Royal Sussex County Hospital, opposite the Barry building on Eastern Road.

What should I bring?

If you have previously been under another hospital or have details of other family members who have had problems with their aorta please bring along any relevant hospital letters or information.

Please also bring a list of any medications you are currently taking.

As well as this clinic you may also be invited to see your cardiologist.
Introduction

You have been sent an appointment to attend our Nurse Led Aortopathy Clinic. The word ‘aortopathy’ refers to any disease or problem affecting the aorta, the main artery that carries oxygen rich blood from the left side of the heart to the rest of the body. The clinic is concerned with abnormalities of the ‘thoracic’ aorta, the part of the aorta in the chest.

You may have heard of Abdominal Aortic Aneurysm and undergone screening for this. We work very closely with the Vascular team at the hospital and they specialise in the care and management of this type of aortic dilatation.

How is an dilated aorta detected?

Patients with aortic problems often get no warning symptoms; their aortopathy may be picked up as a coincidental finding during tests for other conditions. It may be discovered following genetic testing of other family members, or it may go unnoticed and only be diagnosed when there is a severe problem that can be life threatening and this usually requires emergency surgery.

Why have I been referred to the clinic?

There are several reasons why you may have been referred to the clinic:

- You have already been diagnosed with an dilated aorta by your cardiologist
- You have already had surgery on your thoracic aorta
- You have an inherited condition that is associated with weakening of the aorta e.g. Marfan syndrome, Turner syndrome
- You may have a close relative who has experienced a dilated aorta or experienced aortic dissection (a tear in the aorta) and genetic testing has identified genes that may increase your risk of having a dilated aorta

What can I expect?

You will be referred for imaging such as a CT scan, MRI scan or echocardiogram to look at the aorta in detail. You will be seen in clinic by an experienced Cardiac Nurse Specialist who will be working closely with our team of Consultants to monitor your aorta at regular intervals, usually annually.

The nurse will check how you are getting along, review your test results and give you lifestyle advice to minimise the risk of problems developing.

It’s important that we perform these tests and follow up with you so that we can keep a close eye on your aorta and check for any changes over time.

If there are changes to the aorta these will be discussed and explained to you. Surgery or other forms of intervention can then be planned and performed when you are fit and well rather than being undertaken as an emergency. Genetic testing may be advised for some people.