North Thames Family Support Guides

Thoracic Aortic Conditions

Supporting families after a sudden death caused by a thoracic aortic condition



Before you begin

First of all, I am so sorry that you and your family are going through this.

Losing someone you love is overwhelming. It is completely understandable if this guide feels like more information than you can take in right now.

Some of the information in this guide may be new to you. You do not need to understand everything straight away. If you have questions, or something does not make sense, you can ask your healthcare team to talk it through with you.

There is no expectation that you read it all today. You may find it helpful to come back to different sections over time.

This guide explains why we may recommend screening, why DNA may sometimes be stored, and what happens next.

It is here to support you.

Understanding your loved one's condition

The aorta is the largest blood vessel in the body. It carries blood from the heart to the rest of the body.

Sometimes the wall of the aorta can become weakened and the aorta can enlarge. A more significant enlargement may be called an aortic aneurysm. A tear can also develop in the wall of the aorta. This is called an aortic dissection.

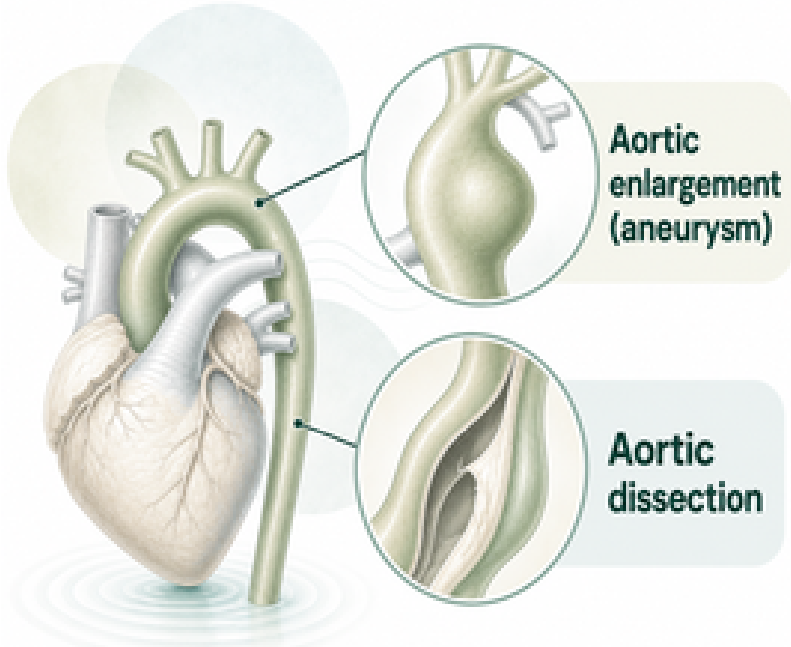
Some conditions affecting the aorta can be inherited, meaning they can run in families. Because of this, we may recommend screening for close relatives.



What can happen to the aorta?

The aorta can gradually become enlarged. A more significant enlargement may be called an aortic aneurysm.

An aortic dissection happens when a tear develops in the wall of the aorta. Blood can then flow between the layers of the wall, causing them to separate.



Why did this happen?

There are different reasons why the wall of the aorta may become weakened.

Sometimes this can be related to factors such as high blood pressure. In other people, there may be an inherited tendency for the aorta to become enlarged or to dissect.

Sometimes there may be more than one contributing factor, and it is not always possible to know exactly why an aortic dissection happened.

Because an inherited cause may still be possible, we may recommend screening for close relatives, even when there is no known history of an aortic condition in the family.

What symptoms can an aortic aneurysm cause?

Most people with an aortic aneurysm have no symptoms and feel completely well. This is why screening is important.

Sometimes, particularly if the aorta becomes more enlarged, symptoms can occur. These may include:

- pain or discomfort in the chest or back
- breathlessness
- a persistent cough or hoarse voice
- difficulty swallowing

These symptoms can have many other causes and do not necessarily mean that you have an aortic aneurysm.

What does this mean for my family?

Some thoracic aortic conditions can be inherited, meaning they can run in families. A relative may therefore have an aortic condition even if they feel completely well.

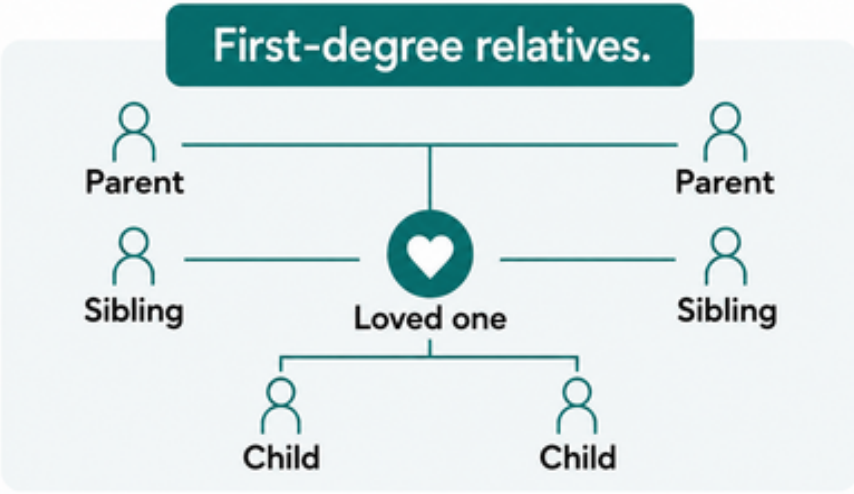
Changes in the aorta can develop without causing any symptoms. This is why we may recommend screening for close relatives.

Screening can help us identify whether there are any changes in the aorta that may need monitoring or treatment.

Who should have screening?

We usually begin by offering screening to your loved one's first-degree relatives.

The results of screening, together with what we learn about the family, will help us decide whether any other relatives may also need screening.



What does screening involve?

Screening involves tests that look at your aorta and heart.

These tests help us check the size and shape of your aorta and look for any changes that may need monitoring.

You may not need every test, and they do not always need to happen on the same day.

ECG
Stickers are placed on your chest and connected to a machine that records the electrical activity of your heart.

Echocardiogram
An ultrasound scan of your heart that can also look at the part of the aorta closest to your heart.

Screening continued

CT scan
A scan that can give detailed pictures of your aorta. It is not usually performed at the first appointment.

MRI scan
A scan that can give detailed pictures of your aorta. It is not usually performed at the first appointment.

You may not need both of these scans. Your healthcare team will explain if either is recommended for you.

What happens next?

The first step is usually to ask your GP for a referral for screening **(or take the letter I provided to your GP).**

GP referral

Tests

Clinic appointment
Discuss your results and questions with the cardiac team.
This may be on the same day as your tests or on a different day.

After screening
The team will explain whether you need any further tests, monitoring or follow-up.

What happens after my screening?

Once your tests are complete, the cardiac team will explain the results and what they mean for you and your family.

If your screening is normal
This is reassuring. You may need screening again in the future because changes in the aorta can sometimes develop over time.

The cardiac team will advise you if and when you need to be screened again.

If your screening shows something
Sometimes screening identifies changes in the aorta that need further investigation or monitoring.

The cardiac team will explain what the results mean for you and your family.

If an aortic condition is found

If further investigations confirm that you have an aortic condition, your cardiac team will talk to you about what this means for you.

Not everyone will need treatment. Depending on the changes in your aorta and your individual circumstances, you may be offered:

- regular scans to monitor your aorta
- medicines to help control your blood pressure
- advice about exercise and physical activity
- in some people, an operation to repair the aorta

Any treatment or follow-up will be tailored to you and the condition that is found.

• Storing DNA

A tissue sample may have been stored after your loved one died. DNA can be extracted from this sample and stored in case genetic testing may be helpful now or in the future.

DNA can be stored for many decades. Storing it does not mean that genetic testing has been carried out.

Keeping DNA stored simply keeps this option open for your family.



DNA extraction and storage usually takes around **6–8 weeks.**

• Will genetic testing be carried out?

No. Genetic testing is not carried out automatically.

The cardiac and genetics teams will consider the post-mortem findings, family history and results of screening when deciding whether genetic testing may be helpful.

If genetic testing is recommended, you will be given a separate guide explaining genetic testing, what the results may mean, and what this could mean for your family.

Things I don't want to forget

You can use this page to write down questions, things you would like to talk about, or anything you want to remember.

Support and resources

You may find these sources of information and support helpful.

The Aortic Dissection Charitable Trust – aorticdissectioncharitabletrust.org
Information and support about aortic dissection.

SADS UK - sadsuk.org
Bereavement support for families affected by sudden cardiac death.

British Heart Foundation - bhf.org
Information and support about heart and circulatory conditions.

Amber's story
A parent shares her experience after loss.
NT GMS website: 'Highlighting our Sudden Cardiac Death project'.

The Ripple

A family member once described the impact an inherited condition can have on a family as being like a stone dropped into a pond. The ripples spread outwards, touching every member of the family in different ways.

Those words have stayed with me ever since.



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This guide has been developed to support families following a sudden death.

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