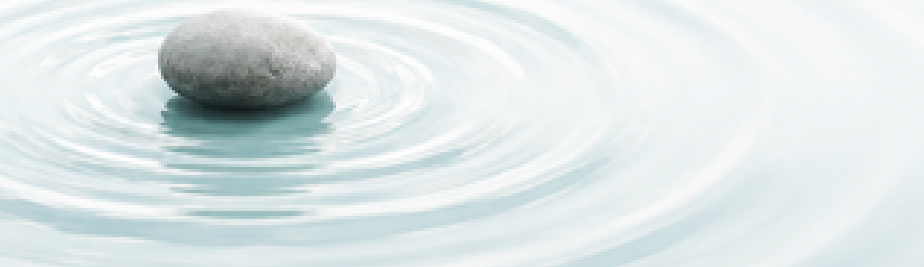
North Thames Family Support Guides

Heart Rhythm Conditions

Supporting families after a sudden cardiac death (Sudden Arrhythmic Death Syndrome - SADS)



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 cardiac screening, why DNA may sometimes be stored, and what happens next.

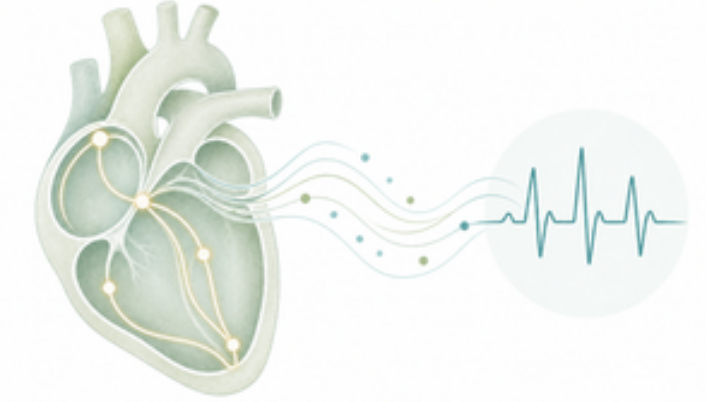
It is here to support you.

Understanding your loved one's condition

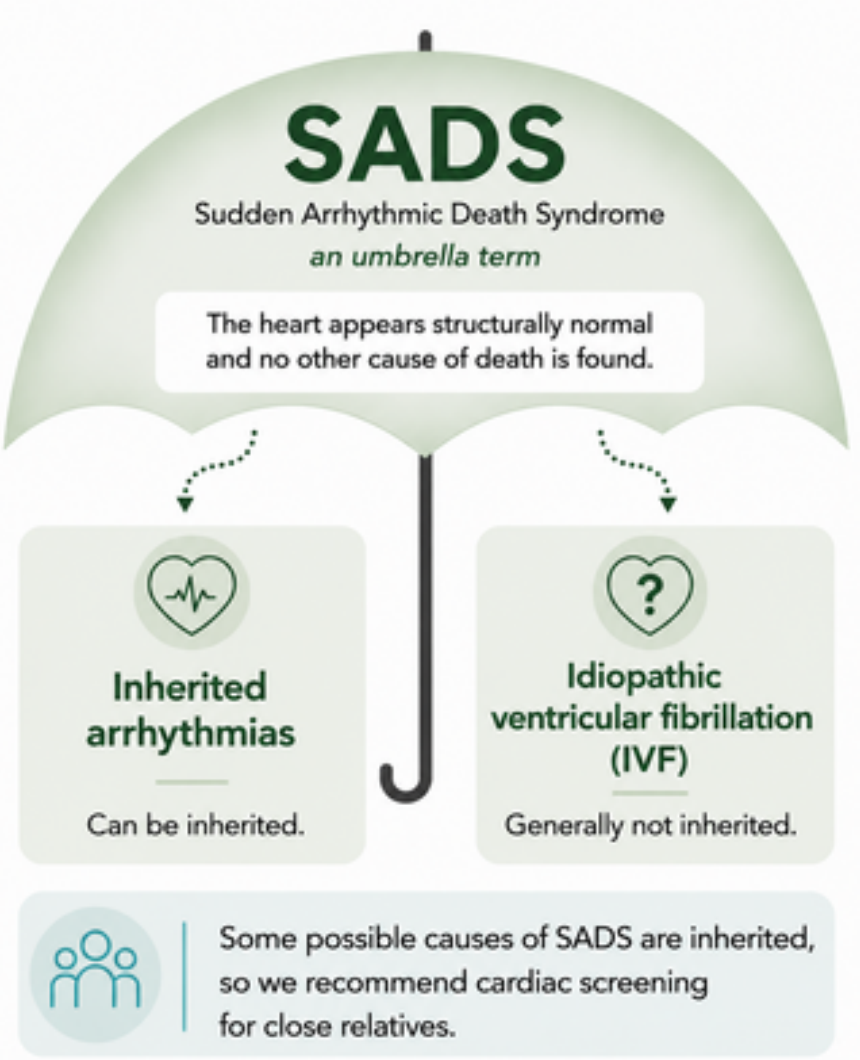
Sometimes, a sudden cardiac death is caused by a condition affecting the electrical system that controls the heart's rhythm. Some of these conditions can be inherited.

You may hear this described as a problem with the "electrics of the heart."

These conditions can sometimes cause the heart to develop a dangerously abnormal rhythm (arrhythmia). The heart itself may look completely normal, including at post-mortem examination.



- **What does SADS mean?**



Inherited heart rhythm conditions

There are several inherited conditions that can affect the electrical system of the heart. They include:

Long QT syndrome (LQTS)
A condition that affects the heart's electrical activity.

Brugada syndrome
A condition that can cause abnormal heart rhythms.

Inherited heart rhythm conditions continued

Other inherited heart rhythm conditions include:

Catecholaminergic polymorphic ventricular tachycardia (CPVT)
A condition where abnormal heart rhythms can be triggered by exercise or strong emotion.

Less common inherited rhythm conditions
These include Short QT syndrome and progressive cardiac conduction disease (PCCD).

Idiopathic ventricular fibrillation (IVF)

Idiopathic ventricular fibrillation (IVF) is a diagnosis that can sometimes be made in someone who survives a cardiac arrest.

They will have detailed heart tests to look for a cause, including inherited heart rhythm conditions. If no cause is found, they may eventually be diagnosed with IVF.

IVF is generally not inherited.

After a sudden death, we cannot carry out these detailed tests on the person who died. This means we cannot know whether IVF was the cause. **IVF is one of the possible causes included under the umbrella term SADS.**

What symptoms can heart rhythm conditions cause?

Some people with a heart rhythm condition can have no symptoms and feel completely well. Others may experience:

- Palpitations - feeling your heart racing, pounding or skipping beats
- Fainting or feeling faint

Symptoms can vary depending on the type of heart rhythm condition and from person to person.

What does this mean for my family?

Some of the heart rhythm conditions that can cause SADS are inherited. This means they can be passed down through families.

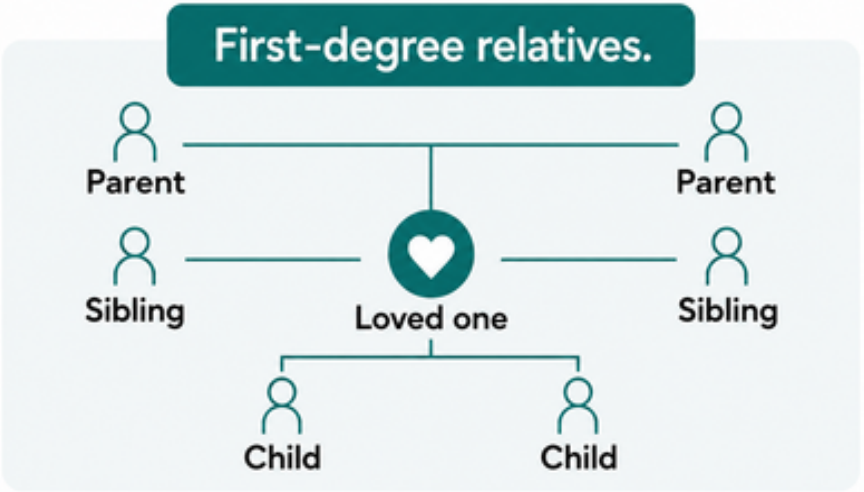
Cardiac screening can help identify signs of a condition before it causes problems.

Because we do not know the exact cause of your loved one's death, we recommend cardiac screening for their close relatives.

Who should have cardiac screening?

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

Screening may then be recommended for other relatives, depending on the results and what we learn about the family.



If your screening is normal, relatives on your side of the family will not usually need cardiac screening.

What does cardiac screening involve?

Cardiac screening involves a number of tests that look at the structure and electrical activity of your heart.

These tests are routinely used to help us build up a complete picture of your heart. Most people find them straightforward, and most are painless.

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 looks at its structure and how well it is working.

Cardiac screening continued

Exercise test

You walk on a treadmill while your heart rhythm is monitored. The test usually takes around 10–15 minutes.

Heart monitor

A small wearable monitor records your heart rhythm over one or more days, usually while you go about your normal activities.

Cardiac MRI

A scan that takes detailed pictures of your heart. **This is not needed for everyone** and is usually only arranged if additional information is needed.

What happens next?

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

GP referral

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Cardiac tests

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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.

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After screening
The team will explain whether you need any further tests 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. If you are an adult and all the recommended tests are normal, you will usually not need ongoing cardiac screening.

Relatives on your side of the family will not usually need cardiac screening.

If your screening shows something
Sometimes screening identifies signs of a heart condition that needs further investigation.

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

If a heart condition is found

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

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

- regular heart checks and follow-up
- medicines to help reduce the risk of an abnormal heart rhythm
- advice about exercise, medicines or other things that may trigger an abnormal heart rhythm
- in some people, a device such as an implantable cardioverter defibrillator (ICD)

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 cardiac screening when deciding whether genetic testing may be helpful.

If genetic testing is recommended, we will give you 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.

SADS UK – sadsuk.org
Support for families affected by SADS and inherited heart rhythm conditions.

Cardiac Risk in the Young (CRY) – c-r-y.org.uk
Support for families affected by sudden cardiac death.

British Heart Foundation – bhf.org
Information and support for people and families affected by heart 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 cardiac death.

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