



**IRISH HEART
FOUNDATION**
Fighting Heart Disease & Stroke


SADS SUPPORT GROUP IRELAND



SADS Support Group in Ireland

This is a voluntary group, set up in 2006 in association with the Irish Heart Foundation, it grew from the friendship of parents who suffered the loss of a young person to Sudden Arrhythmic Death Syndrome (SADS). While we call ourselves the SADS Support Group, we support families who suffer the sudden cardiac death (SCD) of a young person due to any cause - be it a heart rhythm disorder such as Long QT syndrome, a heart muscle disorder such as cardiomyopathy, an infection such as myocarditis, or an accident such as a blow to the chest.

- If you have lost someone to SADS or SCD, through our informal network, we can put you in contact with others who have had a similar loss.
- We can help you get in touch with accredited bereavement counsellors.
- If your family needs to go a screening centre for inherited heart conditions or needs to get more medical information, we can direct you on where to go.
- Depending on the cause of SADS or SCD, you may find it helpful to link with other support groups. The Irish Heart Foundation has set up support groups for people with Long QT Syndrome, Cardiomyopathy and people with ICD devices. We can put you in contact with these groups.

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- Committee members can be contacted on 087 3232552 or via the National Heart and Stroke Helpline on Locall 1890 432 787.

Our group is working to:

- Support families that have been affected by SADS or SCD.
- Increase awareness of SADS and Sudden Cardiac Death (SCD).
- Promote heart checks for young people.
- Encourage communities, businesses, sports venues and schools to train people in CPR (cardiopulmonary resuscitation) and to have access to an AED (automated external defibrillator).

Introduction

You are probably reading this booklet because someone you know has died suddenly and unexpectedly from a heart condition. There is so much to take in, you are dealing with the shock and grief of losing a relative or friend, and trying to understand what happened. At the same time, if the person was a close relative, your doctor may want you and other family members to have some tests to see if you have the same heart problem as the person who has died.

What is Sudden Arrhythmic Death Syndrome (SADS)?

You may have heard about Sudden Cardiac Death (SCD), this is a general term for sudden and unexpected death due to a heart condition. In most cases, when the person's heart is examined at autopsy, a problem with the structure of their heart or their coronary arteries (coronary artery disease) is found that helps explain what happened. However in about 5 percent of cases, the person's heart and arteries appear normal and no obvious cause of death can be found. These deaths are known as Sudden Arrhythmic Death Syndrome (SADS).

Sudden Arrhythmic Death Syndrome (SADS) happens when a person's heart has a serious abnormal heart rhythm which comes from the lower chambers of their heart (a ventricular arrhythmia). This arrhythmia stops the heart from pumping enough blood around the body and leads to cardiac arrest.



What is cardiac arrest?

Your heart is a hollow muscular organ. Its job is to pump oxygen-rich blood to your brain and other organs. If the heart stops pumping blood around the body, a person will quickly become unconscious and die within a few minutes. This is known as cardiac arrest. If the person is quickly given CPR and an electric shock from an AED, their normal heart rhythm can sometimes be restored.

What causes SADS?

The main cause of SADS is a group of heart conditions known as ion channelopathies.

Ion channelopathies

Ion channelopathies affect how your heart's electrical system works. Long QT Syndrome and Brugada Syndrome are two types of ion channelopathies. For more information, see the Long QT Syndrome Support Group's information leaflet.



Structural heart problems

Sometimes changes in a person's heart structure are so slight that there is not enough evidence to prove a different cause of death other than SADS. This can happen even if there is a family history of inherited diseases of the heart muscle and valves. Cardiomyopathy, a disease of your heart muscle, is the most common cause of SADS due to structural heart problems. For more information, see the Cardiomyopathy Support Group's information leaflet.

Other causes

Other causes of SADS include electrocution, viral infection of the heart (myocarditis), blow to the chest and adverse reaction to drugs, both legal and illegal substances.

Post mortem

After a sudden, unexpected death, it is likely that a post mortem examination will be carried out on the person who has died. Difficult as this is, it is vital to try and identify the cause of death. This information can help doctors assess possible risks to other family members. The coroner, pathologist and family doctor all have important roles in this investigation.

Does taking part in sport cause SADS or SCD?

No, sport and physical activity are good for your heart. However if a person has a serious, undetected heart problem, over-exertion during sport can act as a trigger for a ventricular arrhythmia that can result in cardiac arrest and possible death.

Who is at risk of SADS or SCD?

- As most cases of SADS or SCD are due to inherited heart conditions, any affected family member is at risk. If a person has been diagnosed with a particular heart condition, and is being treated with medicines and sometimes devices such as pacemakers and ICDs, this risk is greatly reduced.
- It can happen to people of all ages – adults and children.
- It is not always associated with sport – athletes and non-athletes are equally at risk.
- Unfortunately it can happen in active, apparently healthy people. The first symptom of a heart problem can be a cardiac arrest.

Am I at risk of SADS?

A family history of sudden unexplained death, particularly of people under 50 years of age could suggest that there is an inherited heart problem and risk of SADS or SCD in your family. A history of cot death (Sudden Infant Death Syndrome – SIDS) is also very relevant.

While all of the conditions responsible for SADS or SCD are different, there are a number of symptoms that may be linked to these heart problems. If you experience any of these symptoms, you should discuss them with your doctor:

- Feeling breathless with light levels of physical activity.
- Chest pain when you exercise or when you are resting.
- Unexplained dizziness, fainting or blackouts.
- A fast heart rate that comes and goes, even when you are resting.
- Palpitations.

Investigations for possible heart problems will include:

- A review of your family's medical history.
- A physical medical examination.
- An electrocardiogram (ECG) and an echocardiogram (Echo). These tests look at the electrical activity and structure of your heart. They are painless and non-invasive.
- Other tests may be needed.

When a person's heart stops, can anything be done?

If a person is unresponsive and has no signs of normal breathing:

1. Get help. Dial 999 or 112 and ask for an ambulance.
2. Starting CPR quickly can double a person's chance of surviving. If you are trained in CPR, follow the instructions you learned on your training course.
3. If you don't have CPR training, use your hands to push hard and fast on the centre of the person's chest. This will help pump some blood to the brain and other organs. Keep doing this until the ambulance, or someone with an AED arrives and has attached AED pads to the person.
4. Defibrillation with an automated external defibrillator (AED) delivers an electric shock to the heart. In some cases, this will restore the person's normal heart rate.

Where can I train in CPR and to use an AED?

Training is available through a national network of training organisations, affiliated to the Irish Heart Foundation. Contact the IHF or visit www.irishheart.ie for information.

Medical Terms

AED (Automated external defibrillator)

A machine that delivers an electric shock to help restore a normal heart rhythm. Anyone can be trained to use an AED.

Arrhythmia

Abnormal heart beat. The heart may beat too quickly, too slowly or in an irregular way. Arrhythmias that come from your heart's lower chambers (ventricles) can be life-threatening.

Brugada syndrome

An inherited disorder related to the membranes of heart muscle cells. It can result in life-threatening heart rhythms.

CPR (Cardiopulmonary resuscitation)

Pushing hard and fast on the chest and giving breaths to someone who has collapsed and is unresponsive. CPR helps pump some oxygen-rich blood to the brain and other organs, until medical help arrives.

Defibrillation

An electric shock that is sent through your heart to stop an arrhythmia.

ECG (electrocardiogram)

This test measures the rhythm and electrical activity of your heart.

Medical Terms

Echo (echocardiogram)

Use of ultrasound to view moving images of your heart muscle & valves.

ICD (Implantable cardioverter defibrillator)

A small device that's placed in your chest. It uses electrical pulses (shocks) to help control life-threatening abnormal heart rhythms.

Long QT syndrome (LQTS)

An inherited disorder of the heart's electrical system. It can cause dangerous heart rhythms to develop suddenly.

Myocarditis

An inflammation of your heart muscle, most often caused by a viral infection. However it may also be due to a bacterial infection, rheumatic fever or an adverse reaction to some types of drugs.

Palpitations

A feeling that your heart is beating too fast or skipping a beat. Sometimes palpitations are a symptom of an arrhythmia.

Sudden cardiac arrest

Your heart stops working without warning.



Please make a donation today

The Irish Heart Foundation is Ireland's national charity dedicated to the reduction of death and disability from heart disease and stroke. Over 90% of our funding comes from public and business donations. We depend on your goodwill and generosity to continue our work.

If you found this booklet useful, please help our charity to continue to provide heart & stroke information by donating today.

You can make your donation today:

By post: Irish Heart Foundation,
50 Ringsend Road, Dublin 4

Online: www.irishheart.ie

By phone: 01 6685001

Personal Details

Name: _____

Address: _____

Email: _____

Phone: _____

Mobile: _____

Credit or debit card (one off donation)

Amount:

€250* €100 €50 €25 Other € _____

Card Number:

Exp Date: / Security Code**:

Signature: _____ Date: ____ / ____ / ____

* If you donate €250 in one year (or €21 per month) we can claim tax back at no cost to you.

** Last 3 digits on the signature strip on the reverse of our card.

The Irish Heart Foundation is committed to best practice in fundraising and adheres to the **statement of guiding principles for fundraising** promoting transparency, honesty and accountability. Any personal information you provide will be held in accordance with the Data Protection Acts 1988 and 2003.

SEPA Direct Debit Mandate

Unique Mandate Reference:

Creditor Identifier: IE02ZZZ306322

By signing this mandate form, you authorise (A) the Irish Heart Foundation to send instructions to your bank to debit your account and (B) your bank to debit your account in accordance with the instruction from the Irish Heart Foundation.

As part of your rights, you are entitled to a refund from your bank under the terms and conditions of your agreement with your bank. A refund must be claimed within 8 weeks starting from the date on which your account was debited. Your rights are explained in a statement that you can obtain from your bank.

Please complete all the fields below marked*

*Bank Name: _____

*Address: _____

*Account Number (IBAN): _____

*Swift BIC: _____

Creditor Name: **IRISH HEART FOUNDATION**

Creditor Address: **50 RINGSEND ROAD, DUBLIN 4, IRELAND**

*Type of Payment: Recurrent (Monthly) One-off Payment

* Signature: _____ *Date Signed: _____

Please return completed form to the Irish Heart Foundation.

My monthly instalment amount is:

€21* €18 €15 €10 Other € ____ per month

*A regular gift of €21 per month could be worth an additional €9 from the Revenue Commissioners per month at no extra cost to you.

Your first contribution will be taken on either the 2nd or the 20th of the next available month. Please select which date you prefer.

2nd 20th

You will be notified in writing ten days in advance of your first direct debit. If you wish to cancel within 7 days of a direct debit payment please contact your own bank.

Preferences

I would like to hear about other IHF events, activities, awareness campaigns and appeals. Yes

Do you need a postal receipt: Yes No

More information

Irish Heart Foundation

50 Ringsend Road, Dublin 4

Telephone: 01 6685001

Email: info@irishheart.ie

Web: www.irishheart.ie

National Heart and Stroke Helpline

Telephone: Locall 1890 432 787

Email: info@irishheart.ie

ICD Support Group

Long QT Syndrome Support Group

Cardiomyopathy Support Group

c/o Irish Heart Foundation

Telephone: 01 6685001 or Locall 1890 432 787

Email: info@irishheart.ie

SADS Support Group (formerly, SCD in the Young Support Group)

c/o Irish Heart Foundation

Telephone: 01 6685001, Locall 1890 432 787
or 087 3232552

Email: info@irishheart.ie

CRYP Centre

Adelaide and Meath Hospital, Dublin 24

Telephone: 01 4143058

Family Heart Screening Clinic

Mater Hospital, Dublin 7

Telephone: 01 8034354

Email: familyheartscreening@mater.ie

Heart Rhythm Ireland

www.heartrhythmireland.com

Telephone: 041 6871457

Email: info@heartrhythmireland.com



**IRISH HEART
FOUNDATION**
Fighting Heart Disease & Stroke

**Boston
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Defining tomorrow, today™

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National Heart and Stroke Helpline

Locall 1890 432 787

Monday to Friday 10am to 5pm

Web:

www.irishheart.ie

www.stroke.ie



Funding:

The Irish Heart Foundation is the national charity fighting heart disease and stroke and relies on charitable donations for 90 per cent of its funding. We support, educate and train people to save lives, campaign for patients, promote positive health strategies, support research and provide vital public information. We need your support – through donations, as a volunteer or on our training courses.

This publication is sponsored by Boston Scientific.

Published by the Irish Heart Foundation in 2013. The information provided in this publication was correct and accurate at the time of publication to the best of the charity's knowledge.



Registered charity number CHY 5507