

Department of Health Guidelines

In March 2005 new guidelines were published regarding arrhythmias and sudden cardiac death. These guidelines give important recommendations and advise of the possible hereditary nature of these conditions, giving procedures for families after a sudden cardiac death.

Details of the NSF Chapter 8 arrhythmias and sudden cardiac death can be found on:-

Department of Health: www.dh.gov.uk

Chapter 8 booklet:

www.dh.gov.uk/assetRoot/04/10/52/80/04105280.pdf

Chapter 8 implementation documents:

www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/CoronaryHeartDisease/CoronaryArticle/fs/en?CONTENT_ID=4117048&chk=gUd0zQ

Funeral Services

Your funeral director will be able to help with questions about funeral arrangements. Please note that local byelaws vary and you need to be certain that the cemetery chosen will allow the size and type of memorial that you wish. You should also check the period of time that your memorial may remain in place as this can vary.

The National Society of Allied and Independent Funeral Directors: www.saif.org.uk

National Association of Funeral Directors: www.nafd.org.uk

Emotional Support

The premature death of a healthy person with no prior warning is incomprehensible to most people. The shock and confusion can last for a long time. Your confidence and ability to concentrate may be affected and you may feel helpless and vulnerable. These negative feelings will improve with time and each person will cope with their grief in their own way.

It can be helpful to speak with others who have experienced this type of death. Please contact Anne Jolly, SADS UK for help and support. Tel: 01277 230642

Affiliates:

The SADS Foundation USA
www.sads.org
e-mail: sads@sads.org

The Canadian SADS Foundation
www.sads.ca
e-mail: info@sads.ca

The Helen Kirkland Trust Fund for Cardiac Research
e-mail: helen.kirkland.trust@dial.pipex.com

Memorial Funds

You may like to set up a Memorial Fund in memory of your loved one, many people have found this helpful. Friends and family can donate at special times, such as Christmas, Anniversaries and Birthdays. Some people also like to raise awareness and hold fundraising events. The charity provides promotional items, sponsor forms, posters etc., to assist. Memorial funds are used to benefit the community, such as purchasing medical equipment, supporting research etc. Please contact the charity for details of options available.

Other Useful Contacts

The Bereavement Register can assist with stopping direct mail addressed to the deceased. Tel: 01732 460000

www.the-bereavement-register.org.uk

Arrhythmia Alliance for information about arrhythmia:

www.arrhythmiaalliance.org.uk

British Heart Foundation gives information about cardiac disease: www.bhf.org.uk

Citizens Advice Bureau:

www.adviceguide.org.uk/index/family_parent/family/what_to_do_after_a_death.htm

Cruse Bereavement Care for bereavement support:

www.crusebereavementcare.org.uk

Child Death Helpline: www.childdeathhelpline.org.uk

The Compassionate Friends for bereaved parents:

www.compassionatefriends.org

The WAY Foundation for widows & widowers up to the age of 50:

www.wayfoundation.org.uk

Please make a donation to SADS UK to enable us to support those affected by cardiac arrhythmia and sudden cardiac death.

**SADS UK, 22 Rowhedge, Brentwood,
Essex CM13 2TS.**

SADS Australia

www.sads.org.au
e-mail: sadsau@optushome.com.au

SADS UK are a member of

the Arrhythmia Alliance
www.arrhythmiaalliance.org.uk



SADS UK

**Supporting those affected by
Sudden Cardiac Death**



The Ashley Jolly SAD Trust
Anne Jolly 01277 230642
www.sadsuk.org
e-mail: info@sadsuk.org
Registered Charity No. 1113681

Sudden Cardiac Death

A sudden cardiac death is normally attributed to a heart attack, coronary artery disease (CAD), structural heart muscle disease or cardiac arrest.

In more mature people a sudden cardiac death is often due to a heart attack. A heart attack occurs when blood flow is blocked in a coronary artery.

If your loved one was apparently healthy prior to their sudden premature death, it is possible that an undiagnosed genetic cardiac condition may have caused their death. It is important to establish if any other members of the family could have the same genetic condition so that they may be treated appropriately. It is recommended that family members ask their doctors to refer them to an inherited cardiac disease clinic/genetic centre for assessment. A genetic condition is one that may be passed from one generation of a family to another. www.bshg.org.uk/genetic_centres/uk_genetic_centres.htm

GENETIC CONDITIONS THAT GENERALLY CAUSE PREMATURE SUDDEN CARDIAC DEATH ARE :- HYPERTROPHIC CARDIOMYOPATHY (HCM), LONG QT SYNDROME (LQTS), BRUGADA SYNDROME, CATECHOLAMINERGIC POLYMORPHIC VENTRICULAR TACHYCARDIA (CPVT) AND WOLFF-PARKINSON-WHITE SYNDROME (WPW).

HCM is the most common cause of sudden cardiac death in people under the age of 45 years old. Cardiomyopathy is a disease that affects the structure of the heart muscle and can be detected by a specialist pathologist at post-mortem examination.

LQTS, Brugada Syndrome and CPVT are less frequent causes of death. These conditions are due to a chemical imbalance in the ion channels of the heart muscle cells which result in an abnormal heart rhythm. This abnormal rhythm stops the heart pumping blood efficiently, culminating in cardiac arrest. These conditions of the conduction (electrical) system of the heart are very difficult to determine after death as the heart is structurally normal.

WPW Syndrome is also a condition of the electrics of the heart that affect the heart rhythm and can cause cardiac arrest. Again this is difficult to determine at post-mortem.

The charity SADS UK can provide detailed information leaflets covering these conditions.

www.sadsuk.org

SADS UK, 22 Rowhedge, Brentwood, Essex CM13 2TS

The primary purpose of this leaflet is for guidance; specialist advice should be sought.

The Coroner's Involvement

If a person dies from a diagnosed condition that a doctor has treated within the past fourteen days then that doctor may be able to issue a death certificate. However, if a doctor is unable or unwilling to issue a death certificate then the death has to be referred to the Coroner.

The Coroner is a judicial officer who in some instances will be medically qualified. He will have an Officer who liaises with the bereaved family and deals with the administration. Their duty is to investigate unexplained or unnatural deaths and to determine if there was criminal involvement. It is the Coroner's role to try to identify the cause of death and to establish this he may order a post mortem examination. If a cause of death can be given then the death can be registered in the usual way and the Coroner will usually have no further involvement. If the death is not from natural causes or is unascertainable at the time of examination then an Inquest into the death will be opened so that a funeral can take place. A full Inquest may take place many weeks or months after the death and at the conclusion of the Inquest the death will be registered by the Coroner.

The Coroners Society of England and Wales – www.coroner.org.uk

The Department for Constitutional Affairs – www.dca.gov.uk

Scotland

In Scotland the role of the Coroner is performed by the Procurator Fiscal and the system in place is different from the English model. www.scotland.gov.uk/Publications/2006/04/12094440/4

Post Mortem

If a post mortem is necessary the Coroner should advise the next of kin of the date and time of the examination. The next of kin can be represented by a doctor at the examination, they may also request a second post mortem at their own expense. Usually a post mortem examination is completed within three working days and the body can be released for burial or cremation.

PATRONS:

Professor A. John Camm, St George's Hospital Medical School, London

Dr Michael Vincent, University of Utah School of Medicine

Kanu Nwankwo, Professional Football Player

Sir Stanley Odell

Dr Mary Sheppard, Senior Lecturer/Consultant, Department of Histopathology

Professor Richard Sutton, Consultant in Cardiology

Professor Bob Lewin, Psychologist, The University of York

The post mortem is undertaken by a pathologist who will advise the Coroner of his findings. In many instances of sudden and unexpected death it will be necessary for a specialist to examine small tissue samples and/or whole organs including the heart. The next of kin will be given a full description of all samples retained and their wishes regarding the disposal of the samples at the conclusion of the enquiry will be respected. It may be necessary for a cardiac specialist to examine a heart to determine if the death was of cardiac origin. This examination normally takes up to four weeks. Cardiac conditions can be hereditary and so the next of kin may be asked for their permission to store those samples for subsequent analysis. Tissue samples and organs are retained by the Coroner until his jurisdiction ends.

The Royal College of Pathologists: www.rcpath.org.uk

The Human Tissue Authority: www.hta.gov.uk

Coroners Inquest

An Inquest is a public enquiry that does not allocate responsibility for the death. Its purpose is to establish the identity of the deceased and how, where and when the death occurred and to take registration particulars.

The next of kin will be informed of the date and time of the Inquest and may attend. In some cases they may be asked to give evidence. It is likely that a pathologist will also give evidence of his post mortem findings. This can be distressing for the bereaved and the Coroner is accustomed to families leaving the Court at this time.

At the conclusion of the Inquest the Coroner will usually give his verdict and soon afterwards he will register the death and Death Certificates can be obtained from the Registrar a few days later.

'Inquest' provides an independent free legal and advice service to the bereaved: www.inquest.org.uk



The Ashley Jolly SAD Trust

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Registered Charity No. 1113681