

Department of Health Guidelines

In March 2005 new Department of Health 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

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. Confidence and ability to concentrate is affected and feelings of helplessness and vulnerability are often experienced. 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 information and support. Tel: 01277 230642

SADS UK Memorial Funds

Some people like to set up a Memorial Fund in memory of their 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 heart monitors, defibrillators or supporting research, conferences, support meetings etc. Please contact the charity for details of options available.



This leaflet has been kindly sponsored by the National Association of Funeral Directors (NAFD)
618 Warwick Road, Solihull, West Midlands B91 1AA.
To find your local NAFD member, telephone
0845 230 1343 or visit www.nafd.org.uk

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. For further information see:

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

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

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

Winston's Wish helps children rebuild their lives after the death of a parent or sibling: www.winstonswish.org.uk

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

www.sadsuk.org

Registered in England and Wales No. 5679989
Office: 22 Rowhedge, Brentwood, Essex CM13 2TS

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

Ashley Jolly
sad
Sudden Adult Death Trust

SADS UK

Supporting those affected by Sudden Cardiac Death

Genetic cardiac conditions and procedure following a sudden death

Ashley Jolly
sad
Sudden Adult Death Trust
SADS UK

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

Sudden Cardiac Death

If you have been advised that your relative or friend may have died from a sudden cardiac death, the following information may be helpful.

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 most often due to a heart attack. A heart attack occurs when blood flow is blocked in a coronary artery.

Genetic Implications

However, if your loved one was apparently healthy prior to their sudden premature death, it is possible that an undiagnosed cardiac condition may have caused their death. It is also possible that the condition was genetic, and it is therefore 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.

Details about genetics centres can be found at:
www.bshg.org.uk/genetic_centres/uk_genetic_centres.htm

Genetic conditions that may cause premature sudden cardiac death include :-

Hypertrophic Cardiomyopathy (HCM), Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC), 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 45yrs 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.

ARVC may cause up to 5% of unexpected deaths in people under the age of 65yrs old. Heart muscle is gradually replaced by fibrous scar tissue and fatty tissue.

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 (cardiac arrhythmia). This abnormal rhythm stops the heart pumping blood efficiently, resulting 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 affects the heart rhythm and can cause cardiac arrest. Again this is difficult to determine at post-mortem.

SADS UK heart condition leaflets

The charity SADS UK can provide detailed information leaflets covering LQTS, Brugada Syndrome, CPVT and WPW.

It is advisable to discuss this information with your GP.

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 (legal official) officer, they will often have an assisting officer who liaises with the bereaved family and deals with the administration. The Coroner's 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 Ministry of Justice – www.justice.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 Examination

This is a difficult time, yet we advise that contact is maintained with the Coroner's office so that families are aware of the options available to them.

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 examination at their own expense. Usually a post mortem examination is completed within 3 working days and the body can be released for burial or cremation.

The post mortem examination 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. The tissue samples and organs from this examination are retained by the Coroner until his jurisdiction ends. This is the period of time when the body of the deceased technically belongs to the Coroner.

As cardiac conditions can be hereditary the next of kin may be asked for their permission to store tissue samples for subsequent analysis. For further information see:

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

Pathology Guidelines: <http://www.rcpath.org/index.asp?PageID=687>

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 examination 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 a Death Certificate 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