



CHIEF CORONER

JOINT GUIDANCE FOR CORONERS AND CORONERS' OFFICERS

from

**CHIEF CORONER
BRITISH HEART FOUNDATION
CARDIAC RISK IN THE YOUNG
DEPARTMENT OF HEALTH
NHS ENGLAND**

SUDDEN CARDIAC DEATH: INHERITED HEART CONDITIONS

Introduction

1. The purpose of this Joint Guidance is the saving of lives from premature death arising from inherited heart conditions. The Guidance is provided jointly by the Chief Coroner, the British Heart Foundation, Cardiac Risk in the Young, the Department of Health and NHS England. Coroners will of course be aware that there are other relevant charities in this field including the Cardiomyopathy Association.
2. The vast majority of sudden cardiac deaths (SCD) are caused by coronary heart disease. However, most sudden cardiac deaths in people under 40 years of age are caused by an inherited heart condition, from a fault in a single gene that may be passed from one generation of a family to another.
3. Although the number of persons who die from an inherited heart condition is relatively small, a positive approach may save the lives of other family members who are at risk from the same condition.

Inherited heart conditions

4. The most common types of this condition which can lead to sudden cardiac death are cardiomyopathy and sudden arrhythmic death syndrome (SADS). The former can often be identified at post-mortem examination, if needs be by a specialist cardiac pathologist, from structural changes to the heart's pumping chambers. The latter cannot; at post-mortem examination there is often a complete absence of any structural cardiac abnormality. Instead there are often subtle molecular

changes that affect heart rhythm control, usually inherited as a result of a genetic abnormality.

5. Sudden cardiac death due to coronary artery disease, including myocardial infarction (coronary thrombosis), is not included as an inherited heart condition. Nor usually is congenital heart disease (present from birth).
6. An inherited heart condition may lead to sudden death, often in people under 40 who were previously considered to be fit and healthy. Several professional footballers have died. Fabrice Muamba, the Bolton Wanderers footballer and a top level athlete, was struck down in the middle of an FA cup game and was fortunate to survive. Most commonly it occurs in non-professional athletes, including young adults who die unexpectedly from drowning while swimming.
7. In some cases there may be warning symptoms such as shortness of breath, chest discomfort, rapid heartbeats, dizziness or passing out. In many cases the first sign of a problem is the sudden death of one family member.

Helping the family

8. **Where death from an inherited heart condition is suspected, the pathologist should notify the coroner's officer. Even where the condition is not clearly identified but there is suspicion of it, for example because of the youthful age of the deceased and the lack of other explanation following a sudden cardiac arrest, the coroner or the coroner's officer should be ready to act with a view to saving lives of other family members who may be at risk (first degree relatives).**
9. **In the right case, identified or suspected, the coroner's officer should advise family members to consult their GP with a view to a possible referral for screening at a specialist NHS cardiac genetic clinic.**
10. **Information about local specialist clinics can also be obtained from the British Heart Foundation Genetic Information Service (BHF GIS).**
11. **Screening can also take place at one of CRY's ECG screening clinics for those aged 14-35.**
12. For contact details see below.
13. The first point of call should be the GP but the BHF GIS can help families access a specialist clinic assessment through their GP (similar cost to calling an 01 or 02 number and otherwise no charge for the BHF service).
14. Assessment at a specialist clinic brings two benefits. First, if a family member is assessed to be free from the genetic fault it brings relief for him or her and it reduces the potential future risk of being penalised by insurance companies and other financial organisations. Secondly, those who are assessed to be at risk can be offered appropriate treatment and thereby reduce their risk of sudden cardiac death.
15. The BHF GIS and CRY can also refer family members to other relevant charities who can provide emotional support.

Information for coroners' officers

16. All coroners' officers should have access to the booklets provided by the main charities involved in supporting affected families. A list of those booklets is below.
17. At the very least each coroner's officer should have the BHF GIS card to hand. It has the telephone number and website for the service. The coroner's office should have a supply of cards to give to families who may be at risk (call 0870 600 6566 to order cards, quoting code M112).

18. Contact information

Genetic Information Service

British Heart Foundation
180 Hampstead Road
London
NW1 7AW
0300 456 8383
hearhelponline@bhf.org.uk

Cardiac Risk in the Young

Unit 7
Epsom Downs Metro Centre
Waterfield
Tadworth
Surrey
KT20 5LR
01737 363 222
cry@c-r-y.org.uk

19. Booklets:

Call the BHF on 0870 600 6566 to order the following booklets:

- Supporting families affected by inherited heart conditions: The role of the coroner's officer
- Sudden Adult Death Syndrome
- Arrhythmogenic right ventricular cardiomyopathy
- Hypertrophic cardiomyopathy

Call CRY on 01737 363 6566 to order a copy of the following booklet

Cardiac conditions in the Young: from ARVC to WPW

20. Other useful contacts

Cardiomyopathy Association

Unit 10, Chiltern Court
Asheridge Road Industrial Estate
Asheridge Road
Chesham
Bucks
HP5 2PX

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