

Supporting families following a sudden unexpected death

This leaflet explains the importance of keeping some tissue from a deceased family member to allow for further investigation later.

Why it's important to keep some tissue from your family member

The post-mortem examination of your loved one suggests they could have died from an inherited heart condition. This means they may have had an altered gene which led to the condition.

Inherited heart conditions can be passed on through families. Some people with an inherited heart condition have no symptoms, and the first sign there's something wrong is when someone dies suddenly, with no obvious cause. Your family member may be the only person in the family to develop the condition. However, it is recommended that their immediate family members (parents, brothers, sisters and children) are seen by a specialist doctor to see if they have the same altered gene.

Keeping some tissue may be a hard decision for some people but it is important. Keeping a tiny amount of your loved one's tissue could help doctors, nurses and scientists to better understand the type of heart condition that caused their death. They can better support you in understanding any risks for the rest of the family.

What does keeping my family member's tissue involve?

A very tiny amount of spleen or liver (about the size of a fingernail), or a sample of blood, will be kept and transferred to the NHS. The tissue is labelled and stored in a special fridge. This safely stores the samples, so

that DNA can be extracted for future testing. This can help in understanding more about your loved one's cause of death.

Consent to keep tissue

Your loved one's tissue can't be kept without your consent. When the post-mortem examination was first ordered by the coroner, you will have been informed that tissue was removed as part of the post-mortem examination. You will have been asked what you would like to happen to the tissue at the end of the investigation. As the investigation indicates that an inherited heart condition may have been the cause of your loved one's death, the Coroner's Officer is now asking for your consent to keep a tiny amount of tissue for further testing, if this was not already given.

If you are not comfortable with doing this for any reason, you don't have to give consent. It is your choice. If you would like tissue to be kept, the Coroner's Officer will record your decision and arrange for the tissue to be sent to the NHS. This means the tissue can be used later when you and your family feel ready to see a doctor at a specialist clinic.

What happens next?

Each family will work through the next steps at their own pace depending on their circumstances and how they feel.

When you are ready, the local inherited heart conditions clinic (called the ICC clinic) will be there to help. You'll be supported by a team of doctors, nurses and scientists experienced in caring for families like yours. Some family members may be ready for the tests earlier than others. That's normal and the team at the clinic will be understanding about that.

The Coroner's Officer can send a letter to the local ICC clinic on your behalf if you give them your permission to do so. This means you won't need to remember to contact the ICC clinic yourself. Instead, the ICC Co-ordinator will contact you by letter, email or phone. You can set up an appointment when you are ready.

Where can I get more information about inherited heart conditions?

Losing a loved one suddenly is a very traumatic experience. There are several places you can go for support.

Cardiac Risk in the Young (CRY)

CRY is a charity with the aim of preventing young sudden cardiac deaths through awareness, screening and research, and supporting affected families.

The emotional impact of the sudden, seemingly inexplicable death of a young person on their family cannot be underestimated. CRY offers emotional and clinical support following a young sudden cardiac death. In addition, CRY supports young people diagnosed with potentially life-threatening cardiac conditions and offers bereavement support to families affected by young (age 35 and under) sudden cardiac death. You can call CRY at 01737 363222 or find them online at www.c-r-y.org.uk/



01737 363 222



c-r-y.org.uk

The British Heart Foundation (BHF)

The BHF provides information about Inherited Heart Conditions online at bhf.org.uk or you can call their Genetics Information Service helpline on 0300 456 8383.



0300 456 8383



bhf.org.uk

FAQs

01 How much tissue will be kept?

Often a fingernail-sized sample of spleen or liver is kept to allow genes to be tested. Later, in the ICC clinic (if you give consent), further testing on your loved one's genes may be carried out using the sample.

02 What happens if I don't give consent for the tissue to be kept?

If you would rather not provide consent, the tissue will either be returned to your Funeral Director to deal with or sensitively disposed of in accordance with your wishes.

Immediate family members can still be referred to the local ICC clinic even if consent has not been given for the tissue to be kept. However, if the family is willing to keep the tissue this can help specialists at the clinic better understand your loved one's inherited heart condition and support your family most effectively.

03 Will testing automatically be carried out on my deceased relative's tissue?

No. It is illegal for further testing to be carried out without consent from the family. The team at the ICC clinic will talk to you about this. They will explain what the tests are looking for and what the results would mean. You will be supported by a genetic counsellor/nurse before any genetic testing is carried out.

04 Which ICC clinic will we attend?

The coroner will refer you to the local ICC clinic to start the process. Family members can be seen at different ICC clinics depending on where they live. This can be discussed during the initial contact with the ICC clinic.

05 How long will it be before we are seen at the ICC clinic?

This will vary from clinic to clinic. The ICC clinic will get in touch with you as soon as possible. This is usually within a month after receiving correspondence from the coroner's office. A referral from a GP may be required before being assessed in an ICC clinic. The ICC Co-ordinator will be able to advise and help with this.

06 How long does it take from being referred to finding out if I or other family members could have an inherited heart condition?

The ICC Co-ordinator will explain the process to you and give advice to each family.

07 What happens if we give permission for the tissue to be stored and to be referred to the ICC clinic, but we change our minds?

If you change your mind, the tissue can be returned or disposed of sensitively. You can also tell the ICC clinic that you don't want to be assessed.

If you have any further questions, please contact the team at CRY on 01737 363 222 (10.00am to 5.00pm Monday to Friday) or email cry@c-r-y.org.uk.

You can also contact the BHF's Genetics Information Service helpline on 0300 456 8383 (9.00am to 5.00pm Monday to Friday)

CRY is a registered charity (1050845). The British Heart Foundation is a registered charity in England and Wales (225971) and in Scotland (SC039426).