

How to Start an Inquiry Regarding Organ and Tissue Retention

An Information Leaflet
for Parents and
Relatives

February 2002

Foreword

The Retained Organs Commission has produced this leaflet. The Commission hopes that it will be helpful in providing information on how to start an inquiry about organs and tissues that may have been kept following a post mortem examination.

The Commission is grateful to all those who have contributed to the leaflet.

Other leaflets in this series include:

- Tissue blocks and slides
- Options for disposal of retained organs and tissue; and
- Return of organs and tissue direct to families

What is the Retained Organs Commission?

The Commission was set up by the Secretary of State in April 2001 to help those families who have asked for organs and tissue from a family member to be returned to them. It is also planning the future management of collections.

Does this affect me?

- Organ retention can affect anyone who has lost a relative or child where a post mortem examination has taken place.

Why did the hospital not contact me to tell me if they had retained my child's or relative's organs?

- The Retained Organs Commission decided that families who have been affected by organ retention should not be contacted directly as not all may wish to know that their child or relative has had organs or tissue removed. The NHS has relied on national publicity in the press and on radio and television to encourage those people who want to know more to come forward.

What are retained organs and tissues?

- Retained organs are whole organs and/or pieces of tissue that have been removed at a post mortem examination carried out by a pathologist (a doctor who specialises in the diagnosis of disease by studying tissues).
- They are normally kept for further examination to determine the cause of death or possibly later used for research, teaching, education and training.
- They include organs, or tissue blocks and slides taken from organs. Some major organs are the brain, heart, lungs, liver and kidneys. There are also other smaller organs such as pituitary glands that produce hormones.

What is a post mortem examination and why is it done?

- A post mortem examination, also known as an autopsy, is a surgical examination carried out on the body after death. In some cases organs will be retained. A post mortem examination can be requested by the hospital or ordered by a coroner. Post mortems can tell us a lot about illness and treatment. They help to:
 - identify the cause of death
 - confirm the nature of the illness if this is not already known
 - identify conditions that may not have been diagnosed
 - identify complications and side effects of treatments or drugs
 - help plan future pregnancies in the case of stillbirth or neonatal death
- A coroner orders the majority of post mortem examinations in cases where the cause of death may be sudden or unexpected. The coroner is required by law to do this. He/she does not need the permission of relatives to do this.
- Hospital post mortem examinations need the permission/consent of a relative who will be asked to sign a consent form having been given information about what is involved. A hospital post mortem examination is carried out where a coroner's post mortem examination is not needed, but further information may be required about the cause of death either for the benefit of the family or for the future medical treatment of the condition.

Could organs and tissue have been retained without my permission?

- Yes:
 - where hospital staff were not fully open about what would happen
 - in a few cases where staff acted improperly
 - in many cases the extent of the removal was not made clear
- If your relative or child had a coroner's post mortem examination (usually because the death was sudden or unexpected) you would not have been asked for your permission/consent. The Coroner is required by law to investigate sudden or unexplained deaths and he/she does not need the consent of relatives to ask for a post mortem examination to take place.
- For a hospital post mortem examination you should have been asked to sign a consent form agreeing to the post mortem examination. The consent form may have referred to the retention of tissue or tissue samples. Most people thought this referred only to small pieces of organs. In some cases whole organs have been kept.
- When asked why this information was not made clear to relatives, doctors have said it was because they did not want to cause further distress to relatives and parents at a difficult time.
- Sometimes important information about the cause of death, the disease from which the patient suffered or the effects of treatment requires laboratory investigation of the tissue. This may take days or weeks. In many of these cases organs and tissue kept for investigation would have been disposed of separately by the hospital.

What are tissue blocks and slides?

- Tissue blocks are small pieces of organs. They are normally about 20mm (less than one inch) square and about 5mm (under one quarter of an inch) thick. They can vary in size and in exceptional cases can be much larger. Sometimes they can contain whole organs in the case of small babies.
- The tissue is chemically treated to remove water, which is replaced with wax. The tissue blocks become hard, so that very thin sections can be cut.
- The thin sections are placed on glass slides and stained with special dyes so that the cells can be examined under a microscope. More than one slide may be cut from a block.
- These techniques are the same as those used to examine tissue from living patients for diagnosis.

Am I the right person to make the inquiry?

- You may want to discuss making an inquiry with other family members before deciding to go ahead. Once you have decided you may want to agree within the family who is the best person to make the inquiry.
- Anyone can make an inquiry but information will only be given to close family members, the parents of a child, the next of kin, a close partner or a representative acting on behalf of the family.

Should I make an inquiry?

- Each individual and family will respond differently and will want to deal with this situation in a way that is right for them. Some people make the decision not to find out if organs were kept after the death of a family member, others want to know. Your wishes will be respected whatever you decide.

What do I need to do to before making an inquiry?

- Have ready with you the details of your child's or relative's or partner's full name and address, date of birth, and date and place of death.

How do I make the inquiry?

- Call the hospital where your child or relative died. If you know they died at home or somewhere other than a hospital, call the hospital where they were taken following death. If the hospital has closed contact your local health authority for advice. You can find details in the telephone directory.
- Have ready a pen and paper to take notes of any conversations you may have and always take the name of the person you speak to and their position. Make a note of the date and time that you spoke to them and what was said. Note if they say that they will call you back. Ask when they expect to call you back and let them know when it is convenient for you.

Who should I contact?

- There may be a freephone help line number, or a designated person to speak to. If there is not, ask to speak to the chief executive, who is responsible for running the hospital. The person taking your call will ask for some details before answering any questions. They will need to take details from you before they can help with your inquiry.
- The freephone number for your local hospital will be available from the hospital switchboard or from NHS Direct on 0845 4647.

What should I ask?

- Ask whatever questions you want to, even if they seem insignificant. You may want to prepare and write down questions beforehand. If you do not understand anything that is said to you ask for a clearer explanation.
- The questions most often asked by relatives are:
 - Was there a hospital or coroner's post mortem examination?
 - What organs and/or tissues have been kept?
 - Whose decision was it to keep organs or tissue?
 - Why were they kept?
 - Why wasn't my consent sought?
 - Are they still kept at the hospital?
 - Have they been taken to another hospital?
 - Can I have the organs and/or tissue returned to me?
 - Have they been disposed of?
 - How was this carried out?
 - Are they still being used by the hospital for teaching and education, or research?

- What is the research project?
 - Were organs and tissues from other people kept for the same research project?
 - Can I have a copy of the findings?
 - How is the issue of organ retention being dealt with now?
- Families can ask for copies of medical records and post mortem examination reports. These might be distressing and in some cases quite technical. You may want to get the support and advice of a clinician or family doctor to explain the documents to you.
 - In case you may have further questions in the future it is a good idea to ask for the contact details of someone you can speak to.

How quickly will I hear from the hospital?

- You will not receive answers to your questions immediately. The hospital should keep you informed as to how long it might take to get back to you with the information you have asked for.

How will the information be given?

- The hospital will ask you how you would like to receive the information. It will be either by letter, telephone or at a meeting. You can choose the method that is best for you and your family.
- If you decide to have a face-to-face meeting you may wish to take someone with you for support, and also to take notes of what is discussed.

- All information given verbally should be confirmed in writing by the hospital.
- If you disagree with the hospital's account, write to the hospital and keep a copy.

What information will I receive?

- You should receive information that will say that:
 - no post mortem examination was carried out; or
 - a post mortem was carried out and, if so, whether any organs and tissue were kept, and what may have happened to the organs and tissue.
- In some cases records have been lost or destroyed and the hospital may not be able to give you a definite answer. This is more likely if the death happened a long time ago.
- Where a post mortem examination has taken place it is also possible that tissue blocks and slides may have been sent to a regional or national centre for a second opinion or confirmation of diagnosis. Confirming the location of these will take some time and the hospital will discuss with you whether you wish to continue these further inquiries.

What do I need to do next?

- Begin to prepare yourself and your family for the type of information you might be presented with. Give some thought to whether you or your family would like some additional support to deal with this situation and seek some advice as to what is available locally. You may want to contact a local or national support group or speak to your family doctor.

What feelings might I experience?

- No one can tell you exactly how you will feel. Some families will find that dealing with such sensitive issues reawakens feelings of grief and loss. There is no right way and some people experience a whole range of different emotions at different times. It may help to talk over the way you feel with someone you trust. Each person will grieve in a different way and experience different feelings at different times. You may find it hard to help each other. The hospital can offer information about counselling or other services that may be of help. You can also contact the organisations listed at the end of this booklet if you do not know where to turn for support.

If you have children?

- Sharing information of this nature with children can be difficult. Only you and your family can decide if it is the right thing for you to do and your decision will depend on the age of your children. You may wish to seek advice and support. The people that will be able to discuss this with you are your general practitioner, health visitor, school nurse, teacher, the hospital or one of the organisations listed at the end of this leaflet.

Where can I go for further information, help and support?

Local Organisations

Your local hospital will have an organ retention helpline. Hospital chaplains can offer advice and support as can local funeral directors and crematoria.

Support Groups

Your local hospital will have contact details if a local group exists in your area.

Pity II

Relatives' Support Group

Set up by relatives and parents from Alder Hey, now offering advice nationally.

Stanley Community Enterprise Centre

71 County Road

Walton

Liverpool

L4 3QD

Tel: 0151 285 0016

Fax: 0151 285 0038

Email: pity2@yahoo.co.uk

Website: <http://uk.geocities.com/pity2uk/HTML/>

Stolen Hearts Bereaved Parents Group

Relatives' Support Group

Set up by relatives and parents in Birmingham, now offering advice across the West Midlands.

Cllr Matthew Redmond MBE

1 Chaucer Grove

Acocks Green

Birmingham

B27 7RE

Tel and Fax: 0121 706 9328

National Committee relating to Organ Retention (NACOR)

Relatives' Support Group

Set up by relatives and parents around the country in the wake of events in Bristol, now offering support nationally.

Helpline: 01271 377485

Email: nacor@organretention.org

Website: www.organretention.org

SANDS

Stillbirth and Neonatal Death Society

Provides support for bereaved parents when their baby dies before during or soon after birth.

28 Portland Place

London W1B 1LY

Tel: 020 7436 7940

Helpline: 020 7436 5881

e mail: support@uk-sands.org

Website: www.uk-sands.org

Child Death Help Line

Support offered from bereaved parent volunteers to anyone affected by the death of a child.

Freephone helpline: 0800 282986

FSID

Foundation for the Study of Infant Deaths. Research, support and advice on sudden infant death.

Artillery House

11-19 Artillery Row

London

SW1 1RT

020 7222 8001

24 hour helpline: 020 7233 2090

Fax: 020 7222 8002

Cruse

Offer support to all bereaved people.

National helpline: 0870 167 1677

Website: www.crusebereavementcare.org.uk

The Samaritans

Provides confidential emotional support for anyone in crisis.

National Helpline 0845 790 90 90

INQUEST

Provides advice and information for anyone facing an inquest and has unique experience and knowledge of the inquest system.

Ground Floor

Alexandra National House

330 Seven Sisters Road

London N4 2PJ

Tel: 020 8802 7430

Fax: 020 8802 7450

E-mail: [inquest @inquest.org.uk](mailto:inquest@inquest.org.uk)

Web: www.inquest.org.uk

Child Bereavement Trust

Information and support for professionals and parents

Helpline: 0845 351100

Useful Information

Retained Organs Commission

Retained Organs Commission Helpline: Freephone 0800 092 0203

E-mail: retained-organs-commission@doh.gsi.gov.uk

Web: www.nhs.uk/retainedorgans/index.htm

Natural Death Centre

For inexpensive or environmentally friendly alternatives to conventional burial and cremation.

20 Heber Road

London

NW2 6AA

Tel: 0208 208 2853

Fax: 0208 452 6434


E-mail: rhino@dial.pipex.com

Web: www.naturaldeath.org.uk

Book: The New Natural Death Handbook (£12.99 incl. p&p)

The Retained Organs Commission offers information on the above organisations as a source of help and support for families and relatives. The Commission does not formally endorse the organisations in any way.

The guidance in this leaflet is intended to apply on a general basis only. It does not attempt to (nor can it) anticipate all possible individual circumstances. If you need further information, you may wish to contact one of the organisations referred to above. However, if you are currently involved in litigation arising in connection with the retention or return of organs and tissue and the treatment of your child or relative, or if you consider that there is a possibility of such litigation in the future, you should consider taking specific legal advice in relation to the application of the guidance in this leaflet to your own individual circumstances.



Further free copies are available from:
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It is also available on the website: www.nhs.uk/retainedorgans/index.htm

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