



Retained Organs Commission

Return of Organs and Tissue Direct to Families

An Information Leaflet
for Parents and
Relatives

February 2002

Foreword

The Retained Organs Commission has produced this leaflet to help those families who have requested the return of organs and tissue of a loved one. It deals with safety issues.

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

Other leaflets in this series include:

- Tissue blocks and slides; and
- How to start an inquiry regarding organ and tissue retention
- Options for disposal of retained organs and tissue

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.

What are retained organs and tissues?

- Retained organs and tissues 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 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. The main organs are the brain, heart, lungs, liver and kidneys. There are also other smaller organs such as pituitary glands that produce hormones.
- Tissue blocks are small pieces of organs. The tissue 'blocks' are specially prepared so that they become hard and 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.

I have chosen to have organs and tissues returned directly to me, what will I need to do when I receive them?

- You will need to decide how to dispose of them respectfully or where to store them. The choices are:
 - Burial in a place chosen by the family with arrangements made by the family or via a funeral director
 - Cremation with arrangements made directly with the crematoria or via a funeral director
 - Storage in a safe place in the home or other suitably secure environment

If we choose a burial what do we need to be aware of?

- If families wish to arrange a burial in a place other than a recognised churchyard or cemetery, they will need to contact local planning and environmental officers. Certain requirements need to be met and there may be local byelaws that need to be considered. Some of these are:
 - danger must not be caused to others
 - there must be no risk of contamination to water supplies
 - burial must take place at a minimum depth of at least 3 feet or 90 cms
 - the burial must not interfere with any rights other people may have on the land
 - permission must be gained from the landowner if the land is not owned by the family

- Before deciding to bury in a garden, the family should consider that they might not always be resident at that address.
- Further advice can be obtained from local funeral directors and crematoria and local councils. All will be listed in the local telephone directory.

How can I arrange a cremation?

- You can contact a local funeral director or approach the local crematoria direct. Some crematoria may not be willing to accept tissue blocks or slides for cremation. You need to ask your hospital for advice on what is possible locally.

What does the family need to be aware of if organs and tissue are to be kept at home?

- The hospital will provide you with information about any dangerous substances that have been used as part of the preservation process of the organs or tissues that are being returned to you.
- Many organs are stored in formalin, a substance hazardous to health. When returning organs or tissues preserved in formalin hospitals usually remove the formalin solution and will make sure that they are in a strong sealed container. This will be accompanied with written information advising that the container should not be opened and explaining what to do in the event of an accidental spillage.

- Tissue blocks made from paraffin wax are relatively safe to return. If you are asking for direct return of tissue blocks made in other ways the hospital will consider each request individually to assess the risk involved.
- Older slides may be more brittle and have sharp edges. Information setting out the risks involved will be provided for families.
- Direct return of frozen material could involve risk of infection so the hospital would have to treat each case individually. The hospital may suggest ways of making sure that the tissue is made safe before it is returned. This may change the appearance of the tissue.
- If you think you want to store returned organs and/or tissue at home or in another suitable place you first need to talk to local planning and environmental health officers to make sure your plans are acceptable and satisfy health requirements.

Is there any risk to health?

- Hospitals have a legal obligation to protect the health and safety both of their employees and members of the public.
- To do this, hospitals need to make sure that by returning organs to families they are not putting members of the public at significant risk. They also have to provide information to relatives about the limited risks that returning organs and tissue may involve.
- Families will be asked to confirm that they are aware of and accept the associated risks.

What should I do if I change my mind after having the organs and/or tissue returned?

- If you find you cannot make the arrangements you had planned or you decide that you no longer want to keep the organs or tissue at home you can contact either the hospital or a local funeral director. Both can advise you on what to do.

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 different ways 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 leaflet 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/HTLM/>

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

Web: www.inquest.org.uk

Child Bereavement Trust

Information and support for professionals and parents

Helpline: 0845 357 1000

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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