

Options for Disposal of Retained Organs and Tissue

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 options for disposal of organs and tissue that 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; and
- How to start an inquiry regarding organ and tissue retention
- 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.

What are retained organs and tissues?

- Retained organs and tissue 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 kidney. 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.

The hospital has told us that they have certain organs and tissue from a family member retained. What should we do?

- You can choose. The hospital will discuss with you the choices available for dealing with the organs and tissue. You can take as much time as you need to decide as a family what you would like to do.
- Some of the choices require agreement from local burial or cremation authorities that may not be in place. If these have not been set up in your area they will unfortunately not be available to you. The hospital will explain.

What is respectful disposal?

- Respectful disposal may involve a ceremony that recognises the fact that human organs and tissue are being dealt with. Each hospital has its own procedures so you may like to ask them for further details.

What are the options for respectful disposal, donation or return of retained organs and tissues?

- The options that may be available to families include:
 - Return to families via a funeral director chosen by the family, or by the hospital, for reuniting with the body, or for burial or cremation

- Release to those providing religious burial services e.g. Muslim or Jewish burial councils
- Return to families via a funeral director for a religious ceremony before being returned to the hospital for research and educational purposes
- Retention by the hospital for burial with another family member at a later date (not all hospitals will be able to offer this option)
- Retention by the hospital for respectful disposal at a later date (in cases where retention is a legal requirement, e.g. in criminal cases)
- Donation to the hospital for education or research purposes with the option of future respectful disposal
- Return direct to the family in a sealed casket where there are plans for respectful disposal by the family. (We have another leaflet to help if you choose this option)

Is there anything else we should know before making a decision?

- Cremation of tissue blocks and slides may not always be possible as local crematoria are not always willing to accept them for cremation. Your hospital will advise you what is possible in your local area
- When organs, tissue blocks and slides or babies' bodies are cremated there are usually no ashes.

- Burial may take place in a family burial plot or elsewhere, funeral directors and burial authorities can offer advice on this. If you wish the burial to take place in an area that is not a churchyard or cemetery a funeral director or your local council can advise you.
- Hospitals may also be able to offer information on alternative options such as woodland burial. Further advice can also be obtained from local funeral directors and crematoria.

What will the hospital pay for?

- The hospital will pay for reasonable expenses. These are likely to include the cost of a casket, the cost of a funeral director to collect the casket and take it to the place of burial or cremation and the cost of the burial or cremation itself.

Can the family choose when this will happen?

- Once you have made a decision and informed the hospital a time can be agreed when return and respectful disposal can take place. You may want this to coincide with an anniversary. You should discuss this with the hospital, as they should be able to accommodate your request. A funeral director or a family representative can act for your family at this stage if you do not want to be involved in the process.

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 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/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 and 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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