

*From the Chief Medical Officers for England and Wales*



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25 April 2003

To: NHS TRUSTS, UNIVERSITIES & RESEARCH INSTITUTES

Dear Colleague

***FAMILIES AND POST MORTEMS:  
A CODE OF PRACTICE SETTING STANDARDS IN COMMUNICATIONS WITH FAMILIES ABOUT  
POST MORTEM EXAMINATION,  
MODEL CONSENT FORMS AND INFORMATION LEAFLETS,  
AND AN INTERIM STATEMENT ON THE USE OF HUMAN ORGANS AND TISSUE***

The repercussions of organ retention from post mortem examination, without the consent or knowledge of families, have been considerable. Following the Redfern and Kennedy reports, the Department of Health and the Welsh Assembly Government have been working with all the interests concerned - including the Royal College of Pathologists, other clinicians, NHS Trust organ retention leads, Coroners and their officers, and families - to devise new model consent forms and information leaflets for post mortem examination. These support implementation of a new code of practice *Families and Post Mortems*, which sets out standards of practice in communications with families about both hospital (or consented) and coroners' post mortems.

**Consent forms**

2. Following extensive consultation over the past year, we are publishing the following documents:

*Families and Post Mortems: a code of practice*

Consent form for post mortem examination of an adult

Consent form for post mortem examination of a baby or child

Consent form for the retention and use of tissue and organs following a Coroner's post mortem examination of an adult

Consent form for the retention and use of tissue and organs following a Coroner's post mortem examination of a baby or child

A Guide to the post mortem examination procedure (an information leaflet about adult hospital and coroner cases)

A Guide to the post mortem examination procedure involving a baby or child (an information leaflet about hospital and coroner paediatric cases)

A simple guide to Post Mortem examination procedure (a shorter, summary leaflet relevant to all cases)

3. All of these documents are available at [www.doh.gov.uk/tissue](http://www.doh.gov.uk/tissue) and may be ordered (free-of-charge) from NHS Responseline. Details of how to do this are included in Annex A. A CD Rom containing the "artwork" or text of the consent forms and leaflets is also available for those Trusts who wish to produce their own documents which add to the standards of practice set out in these models, or which may more closely reflect comparable local arrangements. However, we do advise Trusts not to remove elements of the forms as the content has been very carefully considered to represent what we regard as the minimum standards of practice acceptable within the current law and to all parties concerned.

#### **Video for showing to parents**

4. There is also a video *Parents and Post mortems*, which explains the benefits of paediatric pathology, available from the NHS Response line (see Annex A). A video on the procedures for adult post mortem examination will be available later in the year.

#### **Recommended action**

5. We advise NHS Trusts to plan the replacement of post mortem consent forms and leaflets currently in use in hospitals with these new documents and to begin to use these as soon as is practicable and desired. The responsibility for post mortem examinations ordered by the Coroner lies of course with the Coroner. However, if he or she wishes to agree arrangements with an NHS hospital or primary or community care Trust, a shared protocol can be developed of benefit to all concerned. We therefore advise NHS Trusts to consider with their local Coroners any desirable changes in the way that communications with families about post mortem examination currently take place in the light of the good practice guidance contained in this code.

6. The Home Office is sending a similar letter to this one to all Coroners in England and Wales, advising them of the availability of the new forms and leaflets. Joint training or discussion events between NHS staff and Coroner's officers about communications with families have been very useful. Trusts may wish to consider this possibility. The Department of Health has been supporting some initiatives in this area and may be able to advise on training content and other matters.

#### **Review of the law on human organs and tissue**

7. The Department of Health and the Welsh Assembly Government published in July last year a consultation document *Human Bodies, Human Choices* about possible changes to the law in this area. The broad direction of that report was consistent with the

changes we are now introducing. Pending new legislation the enclosed documents are offered as guidance to good practice in this area, compatible with current law, notably the Human Tissue Act 1961. (A report of the responses to the consultation is available at [www.doh.gov.uk/tissue](http://www.doh.gov.uk/tissue) or may be ordered from NHS Response line - see Annex A).

### **Interim statement on the use of human tissue and organs**

8. In the meantime, the Department has drawn up a note of guidance based on the current law. This focuses in particular on the use of organs or tissue for research, training, education, quality control and public health surveillance. Although essentially declaratory of the existing legal position, this too has been subject to widespread consultation and will be kept under review pending new legislation. It is available at [www.doh.gov.uk/tissue](http://www.doh.gov.uk/tissue) or copies may be ordered from NHS Responseline (see Annex A).

### **Guidance on bereavement services**

9. Further guidance will be issued later this year on good practice in the provision of bereavement services. In the meantime, the code of practice *Families and Post mortems* reminds NHS Trusts (at paragraph 5) of their existing obligations under circulars issued in 1992 and 1997.

### **Examination of babies and fetuses**

10. Particular attention is also drawn to paragraph 28 of *Families and Post Mortems*, which reminds Trusts that written consent from the mother should be obtained for the examination of babies and fetuses delivered dead, **regardless of gestational age**. Some Trusts use special consent forms for fetal examination, and these may be more suitable for this purpose than the enclosed models which are designed for babies and children.

### **Further advice**

11. Queries as to the content of this letter, the code, and use of the forms and leaflets should be addressed to Gemma Pearce or Clare Lynley at the following addresses:

[REDACTED]

Clinical Ethics and Human Tissue  
Department of Health  
Room 530B Skipton House  
80 London Road  
London SE1 6LH

12. Queries about the interim statement should be addressed to [REDACTED] at:

[REDACTED]

or at the above postal address.

13. In Wales, all queries should be addressed to [REDACTED]

[REDACTED]

Health and Well Being Strategy and Planning Team  
NHS Wales Department  
Welsh Assembly Government  
Cathays Park  
Cardiff CF10 3NQ

Yours sincerely



**SIR LIAM DONALDSON  
CHIEF MEDICAL OFFICER  
FOR ENGLAND**



**RUTH HALL  
CHIEF MEDICAL OFFICER  
FOR WALES**

**How to order copies of the post mortem consent forms, leaflets, codes of practice, interim statement and report of the *Human Bodies, Human Choices* consultation, and the video *Parents and Post Mortems* from the NHS Response line**

Copies of all the documents may be ordered from:

Department of Health Publications  
PO Box 777  
London SE1 6XH

Tel: [REDACTED]

Fax: [REDACTED]

E-mail: [doh](mailto:doh@nhs.uk) [REDACTED]

Please quote the relevant number and document name as follows:

**Forms**

29767/Consent to a hospital post mortem examination of an adult  
29771/Consent to a hospital post mortem examination of a baby or child  
29769/Post mortem examination of an adult, ordered by the coroner  
29773/Post mortem examination of a baby of child, ordered by the coroner

Please note that copies of the forms may not be available before May 2003.

**Leaflets**

29772/Guide to the post mortem examination procedure  
29770/Simple guide to the post mortem examination procedure  
29768/Guide to the post mortem examination procedure involving a baby or child

If NHS trusts wish to arrange to print their own copies locally, a CD Rom containing the "artwork" is also available for the post mortem consent forms and leaflets by quoting 31732/Post mortem consent forms and leaflets

**Video**

31007/Parents and Post Mortems (video)  
31008/Parents and Post Mortems (CD Rom)  
31235/Parents and Post mortems (DVD)

**Guidance and other relevant documents**

31518/The import and export of human body parts and tissue for non-therapeutic uses - a code of practice  
31519/Families and post mortems - a code of practice  
31520/The use of human organs and tissue - an interim statement  
31521/Human Bodies, Human Choices - a summary of responses to the consultation report

The consultation document *Human Bodies, Human Choices* was published in July 2002 and copies also still available by quoting 28090/Human Bodies, Human Choices

Low resolution 'pdf' versions of all the documents (and other information) are available on the Department of Health website [www.doh.gov.uk/tissue](http://www.doh.gov.uk/tissue). These will enable you to print off further copies of the documents but they will not be of sufficiently high resolution for commercial printing.



# *Families and post mortems*

**A code of practice**



# *Families and post mortems*

A code of practice



## READER INFORMATION

<b>Policy</b>	
<b>Document Purpose</b>	Best practice guidance
<b>ROCR Ref:</b>	<b>Gateway Ref: 1167</b>
<b>Title</b>	Families and post mortems – A code of practice
<b>Author</b>	DH, Clinical Ethics and Human Tissue Branch
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<b>Description</b>	A code of practice on families and post mortems, including sample copies of NHS and coroners' post mortem forms.
<b>Cross Ref</b>	HSC2001/023, drafts of all the documents for consultation
<b>Superceded Docs</b>	
<b>Action required</b>	Implementation of the forms and code of practice from May 2003
<b>Timing</b>	<b>We hope to issue these by May 2003</b>
<b>Contact Details</b>	Clinical Ethics and Human Tissue Branch Room 531B, Skipton House 80 London Road London SE1 6LH
<b>For recipient use</b>	

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This publication is available at  
[www.doh.gov.uk/tissue/families&postmortemscode.pdf](http://www.doh.gov.uk/tissue/families&postmortemscode.pdf)

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## Introduction

1. Post mortem examination is crucially important in informing relatives, clinicians and legal authorities about the cause of death, and in telling bereaved families (who wish to know) about the possibility of acquired and genetic diseases which might need care and treatment. More widely, it is important in improving clinical care, maintaining clinical standards, increasing our understanding of disease, preventing the spread of infectious diseases, and in supporting clinical research and training. Respectful and sensitive communication with bereaved families is essential, both to help them take important decisions at a difficult time, and to ensure continuing improvements in future care.

## Context

2. This code was recommended by the Chief Medical Officer for England in *The Removal, Retention, and Use of Human Organs and Tissues from Post Mortem Examination*, January 2001. It was subject to widespread consultation in the course of 2002 and replaces interim guidance on post mortem examination published by the Department of Health in March 2000. The code has also been formally adopted for use in Wales. It anticipates the current wider review of the law in this area,<sup>1</sup> and the review of the coroners' system.<sup>2</sup>
3. The code is published as part of a wider series of documents about consent in the NHS, as described in Health Service Circular (HSC 2001/023)<sup>3</sup> *Good Practice in Consent*.

## Scope of the code

4. This code sets out recommended practice for all those involved in communicating with families or others close to individuals (both children and adults) and mothers<sup>4</sup> of fetuses who may undergo or have undergone a post mortem examination (whether ordered by the coroner or not). It seeks to ensure:
  - That those close to the person who has died are given the opportunity to understand the reasons for hospital and coroners' post mortems, the processes involved, and their rights in the decision-making process;
  - That the wishes of the person who has died and those close to him or her are ascertained and respected;
  - That organs and tissues are not retained following post mortem without consent or other lawful authorisation (such as that of the coroner);<sup>5</sup>
  - That the disposal of retained tissue and organs, stillborn or miscarried babies, fetal remains, and where possible all products of conception, is in accordance with expressed wishes of the individual (where applicable) or those close to him or her, subject to meeting legal and health and safety requirements; and

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1 *Human Bodies, Human Choices: the law on human organs and tissue in England and Wales*. A consultation report, Department of Health, July 2002. Available at [www.doh.gov.uk/tissue](http://www.doh.gov.uk/tissue) or by telephone 08701 555 455 quote 28090/Human Bodies, Human Choices.

2 The Review of Coroner Services, 100 Pall Mall, St James's, London SW1Y 5HP or [www.coronersreview.org.uk](http://www.coronersreview.org.uk)

3 In Wales – WHC(2002)42. See [www.doh.gov.uk/consent](http://www.doh.gov.uk/consent) for more information about this initiative.

4 Some women who have had a miscarriage or termination may not think of themselves as mothers and professionals should be careful about using this term. Discussion with the father will often also be appropriate.

5 Lawful authorisation may flow from the coroner involved, his or her duty to those who may be charged with an offence, the police and the courts.

- That general information about post mortem examinations is readily accessible, e.g. (as recommended by the Bristol Inquiry report<sup>6</sup>) through the hospital's website, in booklets and on video, and from coroners' offices.
- 5. The code reminds NHS trusts of the requirements to have in place arrangements for bereavement support and advice, and recommends that training is provided or arranged to ensure these are effective, particularly in helping families in which a child dies.<sup>7</sup> The code also advises NHS trusts and universities about giving feedback to families on the subsequent research use of donated tissue.
- 6. The code does *not* deal with body parts or organs held under the Anatomy Act 1984. If the person who has died expressed a wish that their body should be used for medical research under that Act (i.e. for anatomical purposes), it will not be possible to carry out that wish if the body has been subject to a post mortem examination or if any organs except the eyes have been removed for transplantation. These exclusions may need to be explained to the family.
- 7. Arrangements for the return of previously retained organs and tissue to families are set out in guidance from the Retained Organs Commission. This and other information is available on their website at [www.nhs.uk/retainedorgans](http://www.nhs.uk/retainedorgans).

## Patients who are dying

8. This code does not deal as such with the support and information that hospitals should offer to dying patients. However, much of the decision-making after death will be easier if a patient has been able to make known his or her wishes before death. This is obviously a very sensitive matter, which requires staff judgement in each case. However, if it is possible to do so ethically and compassionately, hospitals should help dying patients (and their families) to understand what may happen immediately before and after death, and, while respecting the views of patients who indicate that they do not wish to discuss particular issues, seek to ensure that:
  - Any preferences about what happens immediately before or after their death are identified and understood by staff, including any religious or cultural preferences;
  - That contact is made accordingly with a religious representative, if required;
  - The wishes of the dying person in respect of organ and tissue donation are ascertained and recorded, and the relevant procedures understood, including post mortem examination;
  - Consent is sought for the retention and use of organs or body parts for therapeutic purposes and for medical education or research, and this is recorded;
  - Wishes are ascertained and recorded with respect to the disposal of organs and tissue following post mortem examination, including those which may subsequently be used for medical education or research.

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<sup>6</sup> *The report of the public enquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995: Learning from Bristol/ The Bristol Royal Infirmary Inquiry*. Cm. 5207(II). The Stationery Office, 2001.

<sup>7</sup> HSG(92)8 and HSG(97)43 *People who die in hospital* set out arrangements for bereavement services. These are available on a Department of Health web page ([www.doh.gov.uk/bereavement](http://www.doh.gov.uk/bereavement)). The Department of Health is reviewing guidance on good practice in the provision of bereavement services. Any updates will also be provided on this web page.

9. This broadly applies (although with some important differences) to the parents of terminally ill children, or of babies dying in neonatal intensive care. Although there are difficulties in raising these issues, parents need preparation for what is likely to happen immediately before and after their child's death, and some parents will wish to discuss specific arrangements.

## Post mortem examination (autopsy)

10. A post mortem examination (or autopsy) may take place either because the coroner has ordered it, or because it has been agreed upon by the hospital and the family.<sup>8</sup> This code sets out standards of practice in communications about both.
11. These standards currently form part of an interim framework pending the outcome of reviews of the law on human tissue and of the coroner service. Coroners and their officers may wish to implement these standards as good practice in advance of any changes to the coroners' system, and it would be helpful to do this as part of a locally agreed protocol between the NHS trust and the coroner.
12. In any setting (NHS, academic or other), human tissue or organs may only be removed, retained, or used if there is a proper accountability framework in place which ensures that valid authority is obtained. Before commencing the procedure, the pathologist is responsible for checking that the post mortem examination and any retention or use have been properly authorised, either through the completion of a consent form which must at least meet the standards required by this document, or by the coroner. (This does not imply that the pathologist should be the one to seek consent; see paragraphs 32–34).

## Quality standards

13. The Royal College of Pathologists has produced professional guidelines on autopsy practice<sup>9</sup> to consolidate, update and expand previous guidance. It recommends that post mortem examination should be done according to these guidelines. This code assumes therefore that:
  - An integral part of most post mortem examinations is the removal of tissue samples and indefinite retention of tissue blocks and slides<sup>10</sup> for use in diagnosis, audit and review. This must be explained to the family. Specific consent must be obtained for organs or tissue to be used for research;
  - Medical students, doctors and other health care professionals may witness the post mortem examination or a demonstration of the findings for educational purposes, or for maintaining standards of care. This must also be explained to the family.

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<sup>8</sup> See paragraphs 23–24 for an explanation of the term 'family'.

<sup>9</sup> *Guidelines on Autopsy Practice* – Report of a working group of the Royal College of Pathologists, September 2002. Available at [www.rcpath.org](http://www.rcpath.org).

<sup>10</sup> Small pieces of tissue are removed and placed in small, usually plastic, cassettes. These samples are usually less than 1 cm<sup>2</sup> in size and up to 5 mm thick. (Often samples are much smaller. Samples from the brain may be larger: about 2 cm<sup>2</sup>). The tissue is chemically treated to remove water, which is replaced with wax. These tissue blocks become hard, so that very thin sections can be cut from them. These sections are ten times thinner than a human hair. They are placed on glass slides so that they can be examined with a microscope. More than one section can be cut from one block. These techniques are the same as those used to examine tissue from living patients. Larger organs such as the heart or brain may need to be fixed (preserved with chemicals) for some weeks before blocks and slides can be taken – families need to be advised of this so that they can decide on when and how these organs are to be subsequently disposed of.

## Coroner's post mortem examination

14. A coroner's post mortem examination<sup>11</sup> is carried out according to the provisions of the Coroner's Act 1988 and the Coroner's Rules 1984 in order to determine the cause of death. Although the family's consent is not required, the reasons for the post mortem, and the procedures to be followed, should be explained sensitively to the family. They should be given information about when and where the examination is to be performed<sup>12</sup> and told of their right to be represented at the post mortem by a medical practitioner, if they so desire.
15. A coroner's officer or police officer will usually make contact with the family. If NHS staff perform this role (as part of a local protocol) they would need to consider what advice to give in liaison and agreement with the local coroner.
16. There is legal provision for a copy of a coroner's post mortem report to be provided to the family for a fee, and they should be informed of this fact, when it will be available, and of how to obtain a copy. (No charge is payable for hospital post mortem reports – see paragraphs 47–51 on discussing the results of the post mortem.) Unless the coroner has reason to do otherwise, a copy of the post mortem report should in any case be provided to the deceased's GP, and the family may wish to discuss the findings with him/her.
17. An inquest may also be necessary following post mortem. The reasons for an inquest, and its procedure, should be fully and sensitively explained to the family in these cases. A coroner's officer will usually do this.
18. Following a coroner's post mortem, the family may wish to donate organs or tissue for use in medical education or research, or the person who has died may have expressed such wishes. (This is in addition to the usual retention of tissue blocks and slides for audit and review – see paragraph 13.) Ideally, a request for consent to eventual retention of organs or tissue following completion of the coroner's process should be made *before* the post mortem is carried out, following the same practice (as described in paragraph 19) for hospital post mortem examinations. However, this may be done retrospectively if time does not permit otherwise.

## Hospital post mortem

19. A hospital, or consented, post mortem examination is carried out at the request of the family or the hospital to gain a fuller understanding of the deceased's illness or the cause of death, and to enhance future medical care. During the post mortem examination tissue or whole organs (e.g. the heart) may be preserved for diagnosis, for therapeutic purposes,<sup>13</sup> for future medical education (including assuring the quality of clinical care through audit) or for research. If this happens, it must be in accordance with the provisions of the Human Tissue Act 1961. The valid consent of the family or those close to the deceased person must be given before the post mortem is undertaken to ensure proper compliance with the Act (unless the person who has died has already made a request – see paragraph 26).

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11 About a third of all deaths in England and Wales are reported to coroners, of which slightly less than two-thirds undergo post mortem examination. A post mortem examination may be requested by the coroner where the death is sudden and of unknown cause, and the examination may be able to avoid the need for an inquest. Otherwise, where an inquest is necessary (where the death was unnatural or due to violence or in certain other circumstances), a post mortem examination will normally take place in order to provide the coroner with information as to how the deceased came by his or her death.

12 Coroner legislation requires notice to be given of the date, time and place of the post mortem examination to any relative of the deceased who has asked to be informed, unless it is impracticable to do so.

13 The term 'for therapeutic purposes' is taken from the Human Tissue Act 1961. It is apparent from Parliamentary reports that the only therapeutic use in mind at that time was transplantation (primarily corneal). However, there is no evidence that Parliament wanted to rule anything out, such as quality assurance and audit, which were not recognised concepts when the Act was passed.

20. The Human Tissue Act 1961 provides that the person lawfully in possession of the body of a deceased person (in practice the doctor or other person designated on behalf of the hospital)<sup>14</sup> may authorise the removal of any part from the body for use for therapeutic purposes or for purposes of medical education or research (or simply to establish or confirm the cause of death, or to investigate the existence or nature of abnormal conditions, if applicable) if, having made such reasonable enquiry as may be practicable, he or she has no reason to believe that the deceased expressed an objection or that the spouse or any surviving relative of the deceased objects to the body being so dealt with.
21. While this wording does not refer as such to the need for consent, in practical terms relatives would need to have been informed of, and to understand, the procedures in order for a doctor to establish that there is no objection, and thus that the Act has been complied with.<sup>15</sup> Modern good practice demands this.
22. Similar good practice is recommended in the 1989 Review of the Guidance on the Research Use of Fetuses and Fetal Material, which advised that positive consent should be obtained from a mother<sup>16</sup> to the use of her fetus or fetal tissue, having explained to her the full range of the potential planned options for the use of that fetus or fetal tissue.

## Who can give consent?

23. As noted above, consent **MUST** be obtained for a hospital post mortem, and for the retention and use of organs and tissue in research or education following either a hospital or coroner's post mortem. The 1961 Act used the term 'spouse' or 'surviving relative' to define those to be consulted. Contemporary families may often involve more complex relationships than the traditional spouse or blood relatives – for example, co-habitation without marriage, including with a same-sex partner, or a longstanding relationship without co-habitation. Professionals involved in talking with families and others about consent need to be aware that identifying the most appropriate person to give consent may not be straightforward and staff must be careful not to make assumptions. Careful judgement is needed in each individual case. All competent adult patients are asked to nominate their next-of-kin formally on admission to hospital. Wherever possible, trusts should make clear to patients the reasons for this nomination, and its potential significance (i.e. that this is not simply a contact number). They ought also to make clear that the person nominated as next-of-kin does not necessarily need to be a blood relative or spouse, and may be a same-sex partner, or even a close friend. The last may be particularly appropriate where the individual does not have a close relationship with any family members. Where an individual does nominate such a person, he or she must consider the nominated person's willingness to act in the event of the individual's incapacity or death. It may be helpful for all concerned for NHS trusts to provide such information and advice clearly and routinely in a short information leaflet.
24. Where the person who has died does not have immediate and obvious family members or a nominated representative, all reasonably practicable steps should be taken to trace one. What steps are taken should be documented. If no living relatives can be traced, and there is no evidence of an objection on the part of the deceased person, the hospital may legally carry out the post mortem. However, careful consideration should be given as to whether it is ethically right to do so before the chief executive

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14 Where a dead body is in an NHS hospital or other institution, the person with control and management of the hospital or institution (such as an NHS trust) is the person lawfully in possession of the body until such time as it is claimed by the person who has the right to possession of it for the purposes of disposal. HSC 1998/035 *A Code of Practice for the Diagnosis of Brain Stem Death* required NHS trust chief executives to ensure the existence of an appropriate policy for delegating powers to authorise the removal of organs and tissues from the body so that an appropriate 'designated person' who can provide the relevant authorisation is available at all times.

15 This is clearly argued in more detail in The Royal Liverpool Children's Inquiry Report: *Report/The Royal Liverpool Children's Inquiry*. The Stationery Office, 2001. (HC: [Session 2000–2001]; 112-II).

16 See footnote 2.



(or designate) makes his/her decision. The potential benefits of the particular post mortem in question will need to be weighed against the lack of information about the wishes of the person who has died. Chief executives may wish to take independent advice on individual cases, or consider setting up a formal arrangement to ensure independence of the decision (for example, with the coroner, the chair of the local research ethics committee, or the director of social services). Such decisions must never be delegated to junior staff.

25. Where there is more than one next-of-kin it may not be practicable to trace all of them, and it is therefore unnecessary to do so. In contrast, in other cases, there may be several people who immediately present themselves as next-of-kin, or as otherwise having been close to the deceased person. There may be difficult relationships between these people. In both these cases, if all traced next-of-kin give fully informed consent and there is no known objection on the part of the deceased or any other surviving relatives, a post mortem examination may be carried out. If any of these object, the post mortem should not be done (but see next paragraph).
26. There is no legal obligation to obtain consent from the family if, in accordance with Section 1(1) of the Human Tissue Act 1961, the deceased has left clear instructions, preferably in writing, that his or her body or tissues should be used for transplantation, medical education or research. However, hospitals might prefer nevertheless to discuss this with the family and consider not going ahead with a post mortem or other procedure in the face of refusal or strong opposition from them, in order to avoid any upsetting conflict at a difficult time, or exacerbating the sense of loss. In any case, they will need to discuss the timing of the funeral, and how this might be affected by a post mortem examination.
27. In the case of post mortem examinations on children, consent for the post mortem (and for retention of tissue<sup>17</sup> or organs after the cause of death has been established, in the case of a coroner's post mortem) must be sought from those with parental responsibility. If the child was in care, the local authority may have had parental responsibility. However, even if the natural parents did not have that responsibility, they might reasonably expect to be consulted. Wherever possible discussion should be with both parents, and both should sign the consent form. If either parent is known to object, a post mortem examination should not be carried out.
28. Written consent from the mother<sup>18</sup> must be obtained for the examination of babies and fetuses delivered dead, regardless of gestational age. Although the Human Tissue Act 1961 applies only to those born alive, and in the past consent was not generally obtained for investigations on babies born dead before the age of viability (24 weeks), such practice is now at variance both with contemporary ethical standards and with public expectations.
29. Asking parents to agree to a post mortem examination of their baby or young child is particularly difficult. The Stillbirth and Neonatal Death Society has published specific and detailed guidance for health professionals on managing pregnancy loss and the death of a baby.<sup>19</sup>

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17 See paragraph 13 with regard to tissue blocks and slides. These may be retained without explicit, separate consent as long as this has been explained to the parents.

18 See footnote 2.

19 Nancy Kohner. *Pregnancy Loss and the Death of a Baby: Guidelines for Professionals*. SANDS, 1995. At the time of writing, this guidance was being revised.

## Discussing the post mortem with the family: who may seek consent?

30. The way in which pathological investigation is discussed with the family is extremely important. They need to be given:
- Honest, clear, objective information;
  - The opportunity to talk to someone they can trust, and of whom they feel able to ask questions;
  - Reasonable time to reach decisions (about a hospital post mortem and about any donation of organs or tissue);
  - Privacy for discussion between family members if applicable;
  - Support if they need and want it, including the possibility of further advice or bereavement counselling, or psychological support. (Support may be available from an organisation with whom a relative is already in touch, particularly if he/she has been a long-term carer of the person who has died.)<sup>20</sup>
- Only once the family have had time to reach a decision should they be asked to sign a consent form.
31. Many people carry organ donor cards. The family of the deceased person may well be aware of his or her wishes about donation of organs or tissue for transplantation and raise this possibility. Discussion about donation may have taken place in the hospital, and the family may have decided to donate if possible. All efforts should be made to allow those who wish to donate organs or tissue to do so and explanations should be given where it is not possible. Where organ or tissue donation is a possibility (and it should be made clear that this will involve retention of tissue until it can be used), the person talking to the family should make early contact with the local transplant co-ordinator for advice. There may be local variations, but every hospital should have clear arrangements in place for contacting the co-ordination service or otherwise seeking advice.
32. The person who seeks consent for a hospital post mortem examination should be sufficiently senior and well informed, with a thorough knowledge of the procedure. He/she should have been trained in the management of bereavement and in the purpose and procedures of post mortem examinations. Ideally, he/she should have witnessed a post mortem examination. It is usually the responsibility of the deceased's clinician to seek consent, knowing the medical problems and the unresolved aspects that merit investigation. However, there may be several effective possibilities for who actually discusses the post mortem and obtains consent, and most will involve a team approach. Every trust must have an effective procedure in place. Responsibility for obtaining consent should *not* be delegated to untrained or inexperienced staff.
33. In some hospitals, a trained communicator undertakes the role, with input from the consultant. In others, it may be the consultant or other senior clinician in charge during the patient's last illness, or it may sometimes be a colleague who has been closely involved with the case or has practical experience of such situations. Nurses may be trained to take on this particular role. Wherever possible, consent is best obtained by a person with whom the relatives have an established relationship. If the consultant in charge has not had close dealings with the patient's family during the last illness, the family

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<sup>20</sup> For example, the National Schizophrenia Fellowship gives support to relatives of people with severe mental illness and would be available to help immediately following the death of the person they cared for.

may find it helpful to also have someone present whom they know and trust (such as the hospital chaplain or, in the case of neonatal death, the nurse responsible for their baby's care). However, if someone has died suddenly, there may be nobody who knows the patient or family.

34. Whichever approach is taken, all NHS hospital trusts should have a designated, named individual who is available to provide support and information to families of the deceased where a post mortem examination may be required, whether this is requested by a hospital doctor or a coroner. In some hospitals, this person may also be the one responsible for asking for consent (see previous paragraph).
35. Wherever possible, before the discussion with the family, the responsible clinician should contact the pathologist who will perform the post mortem examination so that accurate guidance can be given on which, if any, tissue or organs are likely to be retained and for what period and purpose. The pathologist may also make him or herself available for a discussion with the family if they wish. If the pathologist is certain that no organs will be retained, then there will be no need to ask the family to consent to this, and the relevant section of the form may be deleted.
36. Meetings about the post mortem, including its timing, should take place in an area with suitable privacy and comfort, away from the clinical area. If a face-to-face meeting is not possible because relatives are unable to attend in person, consent to a post mortem examination may be given orally, by telephone, or electronically, by e-mail. However, the fact of a telephone conversation should be carefully recorded and a copy of the consent form and other relevant documentation provided to the relative, just as with a face-to-face meeting (see paragraph 37).

## What should the discussion cover?

37. The family need to be offered full and clear information about the purpose of the post mortem examination, the procedures and the range of choices available to them. They may need time to consider this. Time may be short; for example, because an earlier post mortem will obtain more or better information. It is helpful for families to know what the time limits are and the reasons for them. Factual information should be provided in a permanent form that allows the family to take it away with them. At the end, they should be provided with a permanent record of the discussion, and of the agreement reached. A signed copy should be included in the patient record and/or coroner's file as appropriate. If possible, the family should have an option of changing their minds, within an agreed time limit. They should be given the name and telephone number and/or e-mail address of the hospital's designated bereavement adviser, so that they can ask further questions later. Ready access to general explanatory material – e.g. a hospital website – may also be helpful. Standardised NHS consent forms for post mortems and accompanying information leaflets have been designed to ensure these points are covered.
38. When discussing the post mortem, some people will wish to know considerable detail about what will be done to the body. In such cases the procedure should be sensitively, but honestly and fully, explained. Others will not want so much or even any detail. This should be respected.
39. The discussion should include:
  - A basic explanation of what happens in a post mortem examination (including the removal, retention and use of tissue samples for diagnosis);
  - The benefits of a post mortem examination and why the doctor thinks it would be valuable in this case, and/or the reasons for the coroner's involvement;

- The possible outcome;
  - Possible alternatives to a full post mortem examination (making clear the limitations to these, and the benefits of a full post mortem);
  - Where, when, and where possible by whom the examination will be performed. For parents in particular, consenting to a post mortem may feel like handing over a part of themselves. They need to know where their child will be, for how long, and when they can have access to the body again. If the post mortem is to be carried out at another hospital, the body should not be transferred any earlier than is necessary and should be returned as quickly as possible afterwards;
  - Information about tests needed (e.g. histology, toxicology) and whether these might cause delays in the process;
  - When, to whom, and how the results of the investigation will be made available and explained;
  - Options for what will happen to the body or remains, and any organs or tissue removed (including tissue blocks and slides), after the examination;
  - Whether consent is to be given for retention or use of tissue or organs after the post mortem, and for what purposes;
  - Explanation of the need for any images to be made (including photographs, slides, X-rays and CT scans), and of their use. In accordance with General Medical Council guidance, specific consent is not needed for the taking of photographs of organs or body parts or of pathology slides. Nor is specific consent needed to use them for any purpose provided that, before use, the images are effectively anonymised by the removal of any identifying marks;<sup>21</sup>
  - Whether organs or tissue can be retained without limit of time for medical research, and whether there are particular uses which the family would wish to exclude from any general consent given;
  - The timing of burial or cremation so that, where possible, any human material removed can be reunited with the body for burial or cremation, if the family so wish. This will need to be done in consultation with the pathologist, and in the case of a coroner's post mortem, with the coroner.
40. In some religions (including the Jewish, Muslim and Hindu faiths), it is important that a funeral should take place as soon as possible, usually within 24 hours. In such cases, every effort should be made to carry out a post mortem examination within that period (if one is required). If this is not likely to be practicable, or if organs cannot be returned within that period, this should be explained to relatives. The family will need the help of hospital staff to get the necessary certification completed urgently before the funeral. In the case of a coroner's post mortem, relatives do not have the option of refusing it, but may want to discuss with the coroner's staff the practical or spiritual implications of any delay.
41. If the pathologist feels that the conditions decided by the family call into question or limit the value of the post mortem, or make it difficult for him/her to carry out a post mortem to a proper professional standard, he/she should advise the family of these limitations or, if necessary, that the investigation should not be carried out. This eventuality should be explained to the family at the time of discussion. However, pressure must not be exerted upon the family; this would render invalid any consent given.

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<sup>21</sup> Guidance on the making and using of visual and audio recordings of patients was prepared by the General Medical Council in 2002 and is available at [www.gmc-uk.org](http://www.gmc-uk.org).

42. Consent for the post mortem must be separate from consent to the retention and use of tissue and organs thereafter. That is to say, the family must be clear that these are two separate decisions. However, whenever possible the family should be asked before a coroner's post mortem takes place whether they might agree to the subsequent retention of tissue and organs removed and their use for certain specified medical purposes once the cause of death has been established and the coroner's duties are complete.<sup>22</sup> (If there is evidence or suspicion of unnatural death, and in coroner's post mortems carried out by Home Office pathologists, different procedures would apply.)
43. The discussion must make clear to the family:
- The meaning of the term human tissue; that it includes organs, parts of organs and tissue in various forms, such as frozen sections and samples fixed in paraffin wax.
  - The various purposes for which tissue might be kept.
  - Options which enable them to give or refuse consent for retention of any particular organ or tissue, and for any particular use.
44. Although staff may recognise the need to obtain a speedy decision in order to maximise the benefit from a post mortem examination, it is important that they do not convey to the family any sense of being rushed. Before the post mortem, many relatives will want to spend as much time as possible with the person who has died and it is important to try to ensure that they have this time. However, if more information or better results might be obtained from an earlier examination, then it is also important that this is explained.

## Cultural traditions and language differences

45. Attitudes to post mortem examination, burial, and the use of organs and tissues after death differ greatly. The individual designated to provide bereavement support must be fully informed in the values and beliefs of a wide range of cultures and religions, and particularly in those of the local community. All health professionals need to be aware of these values and respond to them with sensitivity, and trusts must ensure that the necessary training is given, with support for staff, so that they are equipped to identify and meet as wide as possible a range of possible needs and wishes. However, each case and decision is an individual and personal one, and must be treated as such. The family, from any background, may not always know what is traditional or customary within the community when a death occurs, and may need time to talk to other family and community members.
46. Valid consent can only be given if proper communication has taken place. All trusts must consider the needs of families whose first language is not English. Consent forms should be available in all the main local community languages; and staff should establish whether or not those concerned can read them. If necessary, information should be made available by other means such as video or audiotape. Use should be made wherever possible of a professional interpreter who is trained in interpreting for people who are bereaved. The interpreter must be able to understand and subscribe to issues of clinical confidentiality. In some cases hospital staff have relied on one family member to speak or interpret for the others. However, someone suffering the shock of bereavement may not be in a good position to do this or the individual may not be competent to do so. Children of the family should not be used as interpreters in relation to any formal procedure.

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<sup>22</sup> Coroners' Rule 9: 'A person making a post mortem examination shall make provision, so far as possible, for the preservation of material which in his opinion bears upon the cause of death for such period as the coroner thinks fit.' The Home Office is currently considering amendment of this rule to clarify that the pathologist has no independent right to retain, use or dispose of human material once the coroner's post mortem is concluded, except on the authority of the coroner (in, for example, criminal cases) or with the consent of the family.

## Information to be given to families following coroner's and hospital post mortems

### Results of the post mortem investigation

47. Before any post mortem is carried out, the family should be informed as to when the results are likely to be available. For a hospital post mortem (and for any post mortem on a baby or child – see paragraphs 50–51), they should be given an appointment time (if they want one) that will allow them to discuss the results with the clinician responsible for the care of the person who has died, and/or the pathologist or other specialist clinician where that would be helpful. Families will usually be anxious to receive results of the investigation as soon as possible. They will be better able to tolerate the waiting time if they understand the reasons for it. Trusts will need to plan for the resource implications of this where it has not been standard practice to date. NHS Trusts may also wish to access the 'copying letters to patients' webpage at [www.doh.gov.uk/patientletters/issues.htm](http://www.doh.gov.uk/patientletters/issues.htm) for general information about strengthening accountability to individual patients.
48. If a post mortem is ordered by a coroner, its purpose is to identify the medical causes leading to death, and it should be made clear to the family that the results may necessarily be limited in scope. In such cases, a full discussion might not be appropriate. If the family wish for fuller information from a coroner's post mortem, this might be agreed and the necessary consents recorded in advance. The coroner should be consulted before information about the examination, or any copy of the report, is made available to any other person. If the death is still subject to any inquest, any such discussion may be inappropriate and should be undertaken only with the agreement of the coroner. Families should be warned of this eventuality in advance wherever possible. Coroners' rules regulate access to the post mortem reports provided for coroners, and a fee may be payable for a copy of a report.
49. Some families will not want to know the results of the post mortem, or will not wish to discuss them in detail. Their wishes must be respected. However, the opportunity to discuss them at a later date should remain open to them, and they should be told this.
50. The results meeting (of a full hospital post mortem examination) should allow for as wide a discussion as the family want. Although, in general, information about deceased patients should be treated in confidence, in circumstances such as this, relatives' legitimate wish for relevant information should be met with proper attention and sensitivity. For parents who have suffered pregnancy loss or the death of a baby, for example, the pathology results may raise many issues which it is important for them to discuss as a couple. The issues raised may require further discussion with other health professionals, such as a genetic specialist. Parents should be offered the opportunity of such meetings, with the possibility of taking them up at a later date, and should be given full, written contact information so that they may do so when they feel ready. They should also be told whom they may contact (and how) if they have questions later on, and given details of national and local support agencies.
51. With the permission of the coroner where required, a copy of the full pathologist's report should be offered to the parents of a child who has died. They should be helped with the necessary preparation for what such a report includes. The report should also be given to the deceased's GP and/or treating clinician, and to the mother's GP in the case of a neonatal death or stillbirth. The parents should



be informed that this will be done. Help in interpreting the report should be provided by a relevant clinician. This may be appropriate for adult deaths too.

## Information about use of donated tissue and organs

52. If families have given consent for the retention and use of tissue and organs after the post mortem, they should be asked if they wish to receive (generalised) information about how this is subsequently used, for example through research newsletters or websites. The level of information offered will vary according to use. If tissue is used for teaching, a leaflet on the value of medical education and the contribution of organs and tissue in it may be appropriate. For research, the discussion will need to include how much information they wish to have shared with them. These wishes should be recorded. Any restrictions imposed on the use of tissue, and wishes for its eventual disposal, should already have been clearly documented as part of the process for obtaining consent (see above).

## Maintaining proper documentation

53. Whether or not relatives wish to receive information about use of donated tissue, proper documentation of all tissues and organs retained should be maintained so that at any time the location and use of these is recorded and may be fed back to relatives if this is desired. The pathologist who undertakes the post mortem examination is responsible for ensuring this happens. The initial record should include:

- Details of who gave consent;
- Exactly what the consent related to – which tissue or organs, whether tissue may be used for medical education or research purposes following diagnostic use, and any wishes for disposal;
- What tissue is removed and retained, and how much;
- What is done to the tissue;
- If relevant, when, where and to whom tissue was transferred;
- If relevant, when and how disposal is undertaken.

Where the tissue is used for research, the record also needs to include the date when, the place where, and by whom, ethical approval was granted.

54. A copy of the record should be transferred with any tissue and the record should subsequently be maintained and updated by the person responsible for the storage and/or use of tissue at the receiving site.
55. The pathologist and the hospital should periodically take stock of all human tissue and organs that they have kept from post mortem examinations and report this annually to the trust board.
56. Some parents or relatives may wish to prepare a 'life book' recalling briefly the life of the person from whom tissue or organs has been retained. This may be kept so that it is easily accessible with the tissue or organs.

## Disposal of tissue and organs

57. Tissue and organs should be handled respectfully at all times, in accordance with any reasonable wishes expressed by families or the deceased person.<sup>23</sup> The method of disposal must be legal.
58. Many bereaved people are quite unfamiliar with what needs to be done following a death. The trust's bereavement adviser/officer or the coroner's officer should explain that the deceased's nominated executor (if there is one) has responsibility for the disposal of the body, and provide the family with information about the options available to them for cremation, burial and/or funeral arrangements, the legal requirements, and any other relevant information.<sup>24</sup> This information will probably be needed before the family can make proper decisions about what happens to any tissue or organs retained at post mortem. Staff need to be familiar with hospital arrangements (including those for babies born dead before 24 weeks gestation), what is available locally, basic legal requirements and what arrangements relatives may wish to make for themselves concerning organs and tissue. A summary of this information should be available in a written form (and in an appropriate language) that the family can take away with them. They may wish to discuss it with family or community members before making a decision.
59. Basic options are cremation or burial, and usually a funeral or other religious or non-religious ceremony, either arranged by the family, with help from the hospital if desired, or arranged by the hospital (which is obliged to offer this in the event of a stillbirth: see HSG(92)8, paragraph 3).<sup>25</sup> Relatives may want to be assured about the suitability of any burial or other arrangements made by the hospital.<sup>26</sup>
60. In the case of pregnancy loss, stillbirth or neonatal death, the same options should be available where there is an identifiable body or remains, regardless of size or gestational age. A funeral can be held if parents wish. When there is no identifiable body or remains, parents may still wish to cremate or bury what has been lost. These options should always be offered. Cremation authorities have discretion to permit the cremation of pre-viable fetuses, and tissue removed from pre-viable fetuses. However, the subsequent cremation of tissue removed from stillborn babies is not legally permissible.<sup>27</sup> Some parents who suffer an early pregnancy loss wish to bury their baby's remains respectfully themselves, and staff can support parents in these wishes.
61. Some people will choose not to take part in, or have any involvement with what is done with the remains of their baby or fetus. These wishes must be respected. Those concerned should be told (if they wish to hear) what will happen to their baby's body or remains if they do not take part in the arrangements themselves, and this should be documented. They should be given information about whom to contact if they would like to make different arrangements, and in what timescale.

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23 Guidance was issued by the Retained Organs Commission in July 2001 on the return of organs, tissue blocks and slides, which is available at [www.nhs.uk/retainedorgans](http://www.nhs.uk/retainedorgans). This advises on procedures to be followed if trusts hold previously retained material, for which the wishes of families were not obtained or not recorded.

24 Information on death and bereavement is available on the government website [www.ukonline.gov.uk](http://www.ukonline.gov.uk).

25 In Wales – WHC(91)96 & WHC(92)16.

26 If the hospital does arrange the funeral, arrangements for the burial or cremation should be dignified, involving a simple ceremony if the parents wish. Burial should be in a specially designated, well-kept area. See Department of Health *Welfare of Children and Young People in Hospital*. HMSO, 1991.

27 The separate cremation of organs or tissue removed and retained during a post mortem examination is governed by the Cremation (Amendment) Regulations 2000. Fetuses over 24 weeks gestation may be cremated under the normal cremation regulations relating to stillbirths. However, the subsequent cremation of any tissue retained from stillbirths is NOT included in the Amendment Regulations and would not be permissible. Pending an amendment to the legislation such material will need to be buried or otherwise disposed of as clinical waste. The Cremation Regulations do not apply to pre-viable fetuses (i.e. those under 24 weeks gestation) but cremation authorities may cremate them at their discretion. Tissue removed from fetuses of less than 24 weeks gestation may also be cremated at the cremation authority's discretion. There is no legal duty under burial legislation to bury (or cremate) babies born dead before 24 weeks gestation, but nothing to prevent either option.



62. Where the family have given their consent to the retention of tissue or organs, they should be offered the option of allowing the hospital to dispose of the residual material after its further examination or use. If material is to be incinerated, care should be taken to ensure that the method is appropriate to the material in question. For example, some hospitals have made arrangements for fetal material to be incinerated on its own, following the weekly cleaning of the incinerator, with a short simple ceremony presided over by the hospital chaplain. Alternatively, families may wish the hospital to arrange for collection of tissue or an organ, usually by a funeral director of their choice, at some specified time after the post mortem examination, so that they can make their own arrangements for cremation or burial. Or the hospital may offer to retain the body in storage until the organ can be returned to it. Second funerals and interments of this nature can have significant emotional (and financial) implications for the family and so, while the choice is theirs, the implications of it may be an issue to raise sensitively with them.
63. If the body of the deceased person has already been buried or cremated, and the family request that remaining tissue or organs are to be returned later, these should be released:
- Preferably to funeral directors acting for those who have legitimate responsibility for the disposal of the body;<sup>28</sup>
  - With authoritative confirmation of the identity of the tissue or organ; and
  - With confirmation that the cremation or burial authorities have agreed in principle to accept the remains for disposal.<sup>29</sup>

There is no legal bar to releasing retained material directly to the family, but the proposed method of disposal must be lawful and safe, and it may be difficult to ascertain this. The pathologist should notify the recipient, or the burial or cremation authorities, of any hazards associated with the tissue and its fixative, and obtain confirmation that they are able to handle them appropriately. For example, formalin, commonly used as a fixative, can give an allergic disease of the lungs and is a low grade carcinogen. Because of the potential health hazards, releasing organs and tissue direct to relatives for their indefinite retention is not generally advisable.

## Standardised consent forms and information leaflets

64. To support implementation of this code, the Department of Health and Welsh Assembly Government have produced standardised consent forms and accompanying information leaflets, for hospital post mortems and for coroner's post mortems. These are issued alongside this code as models of good practice. All these documents and further information are available on the Department of Health website at [www.doh.gov.uk/tissue](http://www.doh.gov.uk/tissue). In reviewing their practice, NHS Trusts may decide to replace forms in current use with those issued centrally, or adapt the national forms and leaflets to reflect local arrangements as accurately as possible (although we strongly advise that the standards applied should be no less than those advised nationally). NHS trusts may also wish to agree protocols with coroners locally concerning the use of new standardised forms for post mortem examinations ordered by the coroner.

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28 Hospitals and next-of-kin should be aware that it is the executor of the estate of the deceased (if any) who has responsibility for disposal of the body, so any action must only be taken following consultation with him/her.

29 Further advice is provided by the Retained Organs Commission in its guidance on return of organs, tissue blocks and slides. Although devised for situations where organs are being returned (their having been retained without consent), the advice may nevertheless be helpful in general terms.

## Training and support for staff

65. Training in effective communication and interpersonal skills is important for successful implementation of most aspects of this code, and to enable clinical and other staff to manage bereavement well. This is already required for NHS staff, and more opportunities for training would be welcomed by some coroner's officers.<sup>30</sup> The development of joint protocols between the NHS and the coroner locally may provide opportunities for considering training needs and opportunities in the round, in liaison with the relevant bodies such as the police and local authority.
66. Finally, the death of a patient may be upsetting not only for the family, but also members of the clinical team involved in his or her care. Their needs must be recognised and these should be considered when bereavement services are planned, in training staff in procedures for obtaining consent for post mortem examinations, and in the provision of support at the time of death. Important elements of provision are:
- A supportive working environment and a team or organisational culture in which the impact of loss, and the need for support, are acknowledged;
  - Opportunities for case review and de-briefing;
  - Access to confidential, non-managerial support;
  - Training, so that staff are equipped to manage bereavement and loss, and to handle questions on difficult issues that families may understandably wish to raise.

Department of Health & Welsh Assembly Government  
*April 2003*

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<sup>30</sup> The independent review of coroners' services for the Home Office provides an opportunity to consider these and other issues.

## Further reading

Many organisations provide information, and a number of documents and articles have been published, about bereavement, post mortem examination, and the retention and use of human tissue and organs. They include:

- *Pregnancy Loss and the Death of a Baby. Guidelines for Professionals* (Revised Edition). Nancy Kohner and SANDS (Stillbirth and Neonatal Death Association), 1995.
- *The Fetal and Infant Post Mortem: Brief Notes for the Professional*. Confidential Enquiry into Stillbirths and Death in Infancy (CESDI), 1998.
- *Guidelines in Autopsy Practice*. Report of a working group of the Royal College of Pathologists, September 2002. Available at [www.rcpath.org](http://www.rcpath.org).
- *Tissue Blocks and Slides*. Retained Organs Commission, April 2001.
- *Guidance on Return of Organs, Tissue Blocks and Slides*. Retained Organs Commission, July 2001.
- *Human Tissue and Biological Samples for Use in Research. Operational and Ethical Guidelines*. Medical Research Council (Ethics Series), 2001.
- *Making and Using Visual and Audio Recordings of Patients*. General Medical Council, 2002. Available at [www.gmc-uk.org](http://www.gmc-uk.org).
- *Reference Guide to Consent for Examination or Treatment*. Department of Health, March 2001. Available at [www.doh.gov/consent](http://www.doh.gov/consent).
- *Good Practice in Consent*. Department of Health, November 2001. Available at [www.doh.gov.uk/consent/index.htm](http://www.doh.gov.uk/consent/index.htm).
- *Sensitive Disposal of all Fetal Remains. Guidance for Nurses and Midwives*. Royal College of Nursing, May 2001.
- The Office of Fair Trading published a report of an inquiry into funerals in July 2001, which made recommendations about the information which should be made available about funerals, and the need to ensure sufficient consumer choice. It includes a leaflet prepared in partnership with the National Funerals College. These are available at [www.oft.gov.uk/html/rsearch/reports/oft346.htm](http://www.oft.gov.uk/html/rsearch/reports/oft346.htm).

## Appendix: Sample copies of NHS and coroners' post mortem forms



# Consent to a hospital post mortem examination on an adult

Patient's surname/family name	Consultant (or other responsible health professional)
<input type="text"/>	<input type="text"/>
Other names (if given)	
<input type="text"/>	
Hospital unit number	NHS number
<input type="text"/>	<input type="text"/>
Date of birth	Male/female
<input type="text"/>	<input type="text"/>
Any other relevant details (e.g. preferred language of next-of-kin, religion)	
<input type="text"/>	

This form officially records what you have agreed about what will happen to your partner or relative's body and organs. We realise that this is a distressing time for you but it is important that you understand what you are being asked to give your consent to. Please read the accompanying information leaflet very carefully before completing the form. A member of the hospital staff will explain the content of this form and the leaflet and try to answer any questions you may have.

The form is divided into several sections. You should read each one carefully and discuss it with the hospital staff before completing it.

**Section 1** – Agreement to a full post mortem including removal of body fluids and tissues for laboratory examination, and the taking of X-rays and other images.

**Section 2** – Agreement to a limited post mortem.

**Section 3** – Agreement to use of tissue and fluid samples taken during the post mortem in medical research.

**Section 4a** – Agreement that whole organs and tissue be retained for more detailed examination after the post mortem.

**Section 4b** – Agreement that whole organs retained after the post mortem be donated for medical research, education or audit.

**Section 4c** – Agreement on how any remaining tissue and organs be disposed of following the post mortem.

**Section 5** – Any other specific requests or concerns.

If you are satisfied with the information recorded, sign section 6. The member of hospital staff who has discussed the examination with you will sign section 7, and give you a copy of the complete form.

**You have the right to change your mind within a short time limit agreed with the hospital.** If you wish to ask further questions about the post mortem examination, make changes to what you have recorded on this consent form, or withdraw your consent, please telephone

(contact name and number) as soon as possible and not later than

(date/time). You will be given a copy of the amended form.

## 1. Agreement to a full post mortem examination

I agree to a post mortem examination being carried out on the body of

and I am not aware that he/she objected to this or that another family member has any objections.

### Note

During the examination, samples of body fluids and tissues may be removed for laboratory examination. Tissue samples are made into blocks and slides for examination with a microscope. Any tissue remaining from this process (residual tissue) will usually be disposed of. Blocks and slides are kept indefinitely as part of the medical record or in case they are needed in the future for further tests relating to cause of death or your partner or relative's illness. They may also be used for medical education and audit.

During the examination, photographs, X-rays or other images may be taken. They are usually kept indefinitely as part of the medical record. They may also be used for medical research, education, audit, or quality assurance, in which case information that might allow your partner or relative to be identified would be removed.

## 2. Limiting the post mortem examination

*If you prefer, you may agree to a **limited** post mortem examination (with retention of tissue samples as described in section 1). This will limit the information available about the cause of death or illness, and you must discuss this with the hospital staff.*

Do you wish to limit the examination? YES ☐ NO ☐

If yes, please say how [You may tick more than one box below]:

☐ the head only ☐ the chest only ☐ the abdomen only

☐ other (please describe)

I have discussed this with  (member of hospital staff).

### 3. Agreement to donation of tissue samples for use in medical research (see information leaflet)

If you agree, tissue and/or fluid samples taken as part of the post mortem examination (see section 1) may also be used later in ethically-approved research. This may benefit other patients in the future. Please note it is not always possible to make use of donated tissue.

**Please choose one of the following options:**

☐ **I agree** to tissue or fluid samples already taken as part of the post mortem examination being used for medical research.

☐ **I agree** to tissue or fluid samples already taken as part of the post mortem examination being used for medical research EXCEPT certain types of medical research, as described here:

☐ **I object** to any tissue or fluid already taken as part of the post mortem examination being used for medical research.

**NB: No tissue may be taken primarily for use in research without completion of a specific, separate consent form for that purpose.**

### 4. Consent to retention of whole organs and tissue (taken other than for blocks and slides), their uses and options for disposal

#### *4a Consent to organs and tissue being retained for more detailed examination*

Only a certain amount of information can be obtained at the time of the post mortem examination. In some cases it may be necessary to retain organs and tissue for further, more detailed examination, in addition to the samples described in section 1. This may be needed to find the precise cause of death, or to give a more complete understanding of the illness. If this is necessary in your relative or partner's case, staff will explain the options and implications to you.

**Tick one of the following:**

☐ **I agree** that any organs and tissue may be retained for further investigation, if this is necessary to understand fully the cause of death and effects of treatment.

☐ **I agree** that any organs and tissue may be retained for further investigation EXCEPT the following:

☐ **I object** to any organs or tissue being retained for further investigation.

#### ***4b Donation of whole organs for medical research, education or audit***

If you agree, whole organs removed and retained after the post mortem examination may be kept for future use in ethically-approved research, medical education or audit.

**Please choose *one* of the following options:**

☐ **I agree** to any whole organs which have been removed as part of the post mortem examination being kept for medical research, education or audit.

☐ **I agree** to any whole organs which have been removed as part of the post mortem examination, EXCEPT the following:

being kept for medical research, education or audit.

☐ **I agree** to whole organs which have been removed as part of the post mortem examination being kept for medical research, education or audit EXCEPT for certain types of medical research, education or audit as described here:

☐ **I object** to any whole organs being kept for medical research, education or audit.

#### ***4c Disposal of retained tissue and organs***

After further investigations are complete, what would you like to happen to any remaining tissue and organs (other than those which have been made into tissue blocks and slides for microscopic examination)?

**Please choose *one* of the following options:**

☐ **Return to the body:** I should like the organs and tissue to be returned to the body. I understand that they will not be returned to their original position in the body. I understand that this may delay the funeral.

☐ **Hospital disposal:** I should like the hospital to arrange for disposal of the organs and tissue.

☐ **Return to self/funeral director:** I would like the organs and tissue to be returned to me/the funeral director (*please delete as appropriate*) to arrange lawful disposal. I understand that this may mean that I need to arrange a separate service after the funeral.

## 5. Other requests or conditions

Do you have any particular requests or concerns? If so, please note them here. (Hospital staff should also document here any special consents sought for this case.)

## 6. Signature of next-of-kin (relative or partner)

Name(s)  (PLEASE PRINT)

Signature

Address

Relationship to the deceased person: parent/ husband/wife/partner/brother/sister/other

(please specify)

in the presence of

Name of  
witness\*

Signature

Address

\*Witness may be anyone who is not a member of your family, e.g. friend, neighbour or member of hospital staff.



## 7. Signature of member of staff seeking consent

### I confirm that

- ☐ I have explained to the person completing this form the procedures involved and the reasons for the investigations requested.
- ☐ I have explained what tissue samples, blocks and slides are.
- ☐ I have checked that no objections have been made to the removal or retention of tissues and organs as indicated.
- ☐ I have discussed any special requirements of the case, as follows:

- ☐ I have checked that all parts of the form have been completed.
- ☐ I have provided the following information leaflet(s)

- ☐ I have/have not discussed the case with an appropriate pathologist

(Please name  
pathologist:

)

### Signature of doctor/nurse/other member of staff seeking consent:

Name:

Job title/position

Telephone  
contact number

Bleep

## Notes

1. One copy of the completed form should be given to the next-of-kin or person completing the form, one placed in the patient medical record, and one held by the pathology department or mortuary.
2. If any procedures or uses of material are envisaged which are not pre-printed on this form, separate consent **MUST** be obtained for these and recorded in section 5. Similarly if the pre-printed options do not match the reasonable wishes of the family (e.g. section 4b for certain research only to be done on certain organs only), please record further, preferred option in section 5.
3. If consent for use of tissue, or to carry out a post mortem, is subsequently withdrawn, each page of each copy of the form (or relevant sections) should be clearly struck through. The person taking the withdrawal should also sign and date the form, and note action taken to inform the mortuary (the date and time and name of member of mortuary staff).

# Consent to a hospital post mortem examination on a baby or child

Baby or child's surname/family name	Consultant (or other responsible health professional)
<input type="text"/>	<input type="text"/>
Other names (if given)	
<input type="text"/>	
Hospital unit number	NHS number
<input type="text"/>	<input type="text"/>
Date of birth	Male/female
<input type="text"/>	<input type="text"/>
Any other relevant details (e.g. preferred language of next-of-kin, religion)	
<input type="text"/>	

This form officially records what you have agreed about what you want to happen to your baby or child's body and organs. We realise that this is a distressing time for you but it is important that you understand what you are giving your consent to.

Please read the accompanying information leaflet very carefully before completing the form.

A member of the hospital staff will explain the content of this form and the leaflet and try to answer any questions you may have.

The form is divided into several sections. You should read each one carefully and discuss it with the hospital staff before completing it.

**Section 1** – Agreement to a full post mortem including removal of body fluids and tissues for laboratory examination, and the taking of X-rays and other images.

**Section 2** – Agreement to a limited post mortem.

**Section 3** – Agreement to use of tissue samples taken during the post mortem in medical research.

**Section 4** – Agreement to genetic testing.

**Section 5a** – Agreement that whole organs and tissue be retained for more detailed examination after the post mortem.

**Section 5b** – Agreement that whole organs retained after the post mortem be donated for medical research, education or audit.

**Section 5c** – Agreement on how any remaining organs and tissue be disposed of following the post mortem.

**Section 6** – Any other specific requests or concerns.

If you are satisfied with the information recorded, sign section 7. The member of hospital staff who has discussed the examination with you will sign section 8, and give you a copy of the complete form.

**You have the right to change your mind within a short time limit agreed with the hospital.**

If you wish to ask further questions about the post mortem examination, make changes to what you have recorded on this consent form, or withdraw your consent, please telephone

(contact name and number) as soon as possible and not later than  
 (date/time). You will be given a copy of the amended form.

## 1 Consent to a hospital post mortem examination on a baby or child

## 1. Agreement to a full post mortem examination

I am/We are the parent(s) or legal guardian(s) of [REDACTED]

(baby/child's name, if given) and I/we agree to a post mortem examination being carried out on my/our baby/child.

### Note

During the examination, samples of your baby or child's body fluids and tissues may be removed for laboratory examination. Tissue samples are made into blocks and slides for examination with a microscope. Any tissue remaining after this process (residual tissue) will usually be disposed of. Blocks and slides are kept indefinitely as part of the medical record or in case they are needed in the future for further tests relating to your baby or child's cause of death or illness. They may also be used for medical education and audit.

During the examination, photographs, X-rays or other images may be taken. They are usually kept indefinitely as part of the medical record. They may also be used for medical education, audit or research, in which case information that might allow your baby or child to be identified would be removed.

## 2. Limiting the post mortem examination

If you prefer, you may agree to a *limited* post mortem examination (with retention of tissue samples as described in section 1). This will limit the information available about the cause of your baby or child's death or illness, and you should discuss this with the hospital staff.

Do you wish to limit the examination? YES ☐ NO ☐

If yes, please say what you **DO NOT** want to be examined:

I have discussed this with [REDACTED]  
(member of hospital staff).

### 3. Agreement to donation of tissue and fluid samples for use in medical research

If you agree, the tissue and/or fluid samples taken as part of the post mortem examination may also be used later in ethically-approved medical research. This may help other patients in the future.

**Please choose one of the following options:**

☐ **I agree** to tissue or fluid samples taken as part of my baby or child's post mortem examination being used for medical research.

☐ **I agree** to tissue or fluid samples taken as part of my baby or child's post mortem examination being used for medical research, EXCEPT for certain types of research as described here:

☐ **I object** to any tissue or fluid already taken as part of the post mortem examination being used for medical research.

**NB: No tissue may be taken primarily for use in research without completion of a specific, separate consent form for that purpose.**

### 4. Genetic testing

In certain cases, genetic tests are important to reach a diagnosis.

☐ **I agree** that genetic tests may be done.

☐ **I object** to genetic tests being done.

## 5. Consent to retention of whole organs and tissue (other than for blocks and slides), their uses and options for disposal

### *5a Consent to retention of organs and tissue for more detailed examination*

Only a certain amount of information can be obtained at the time of the post mortem examination, so in some cases we may wish to retain some of your baby or child's organs and tissue for further, more detailed examination. This may be needed to find your baby or child's precise cause of death, or to give a more complete understanding of the illness.

**Please choose *one* of the following options:**

☐ **I agree** that any organs and tissue may be retained for further investigation, if this is necessary to understand fully my baby or child's cause of death and the effects of treatment.

☐ **I agree** that any of my baby or child's organs and tissue may be retained for further investigation EXCEPT the following:

*(Please list organs which may NOT be retained.)*

☐ **I object** to any of my baby or child's organs or tissue being retained for further investigation.

### *5b Donation of organs for medical research, education or audit*

If you agree, whole organs retained after the post mortem examination may be kept for future use in ethically-approved research, medical education or audit.

**Please choose *one* of the following options:**

☐ **I agree** to any whole organs removed as part of the post mortem examination being kept for medical research, education or audit.

☐ **I agree** to any whole organs removed as part of the post mortem examination, EXCEPT the following:

being kept for medical research, education or audit.

**5b Donation of organs for medical research, education or audit (continued)**

☐ **I agree** to whole organs removed as part of the post mortem examination being kept for medical research, education or audit EXCEPT for certain types of research, education or audit, as described here:

☐ **I object** to any whole organs removed as part of the post mortem being kept for medical research, education or audit.

**5c Disposal of retained organs and tissue**

After further investigations are complete, what would you like to happen to any of your baby or child's remaining organs and tissue (other than those which have been made into tissue blocks and slides for microscopic examination)?

**Please choose one of the following options:**

☐ **Return to the body:** I would like the organs and tissue to be returned to my baby or child's body. I understand they will not be returned to their original position in the body. I understand that this may delay the funeral.

☐ **Hospital disposal:** I would like the hospital to arrange for disposal of the organs and tissue.

☐ **Return to self/funeral director:** I would like my baby or child's organs and tissue to be returned to me/the funeral director (*please delete as appropriate*) to arrange lawful disposal. I understand that this may mean that I need to arrange a separate service after the funeral.

**6. Other requests or concerns**

Do you have any particular requests or concerns? If so, please note them here. (Hospital staff should also document here any special consents taken for this case.)

## 7. Signature of parent(s) or other legal guardian(s)

Name(s)

(PLEASE PRINT)

Signature(s)

Address(es)

Relationship to the deceased baby or child: mother/father/other

(please specify)

in the presence of

Name of  
witness\*

Signature

Address

\*Witness may be anyone who is not a member of your family, e.g. friend, neighbour, or member of hospital staff.



## 8. Signature of member of staff seeking consent

### I confirm that:

- ☐ I have explained to the parent(s) or other legal guardian(s) completing this form the procedures involved and the reasons for the investigations requested.
- ☐ I have explained what tissue samples, blocks and slides are.
- ☐ I have checked that no objections have been made to the removal or retention of tissues and organs as indicated.
- ☐ I have discussed any special requirements of the case, as follows:

- ☐ I have checked that all parts of the form have been completed.
- ☐ I have provided the following information leaflet(s)

- ☐ I have/have not discussed the case with an appropriate pathologist.

(Please name  
pathologist:

)

### Signature of doctor/nurse/other member of staff taking consent

Name:

Job title/position

Telephone  
contact number

Bleep

## **Notes**

1. One copy of the completed form should be given to the parent or legal guardian, one placed in the patient medical record, and one held by the pathology department or mortuary.
2. If any procedures or uses of material are envisaged which are not pre-printed on this form, separate consent **MUST** be obtained for these and recorded in section 6. Similarly, if the pre-printed options do not match the reasonable wishes of the family (e.g. section 5b for certain research only to be done on certain organs only), please record any further, preferred options in section 6.
3. If the consent for use of tissue is subsequently withdrawn, each page of each copy of the form (or relevant sections) should be clearly struck through. The person taking the withdrawal should also sign and date the form, and note any action taken to inform the mortuary (the date and time and name of member of mortuary staff informed).

# Post mortem examination on an adult, ordered by the coroner

Patient's surname/family name	Consultant (or other responsible health professional)
<input type="text"/>	<input type="text"/>
Other names (if given)	
<input type="text"/>	
Hospital unit number	NHS number
<input type="text"/>	<input type="text"/>
Date of birth	Male/female
<input type="text"/>	<input type="text"/>
Any other relevant details (e.g. preferred language of next-of-kin, religion)	
<input type="text"/>	

This form and the information leaflet that goes with it should help you understand what is involved in the post mortem examination which has been ordered by the coroner. It officially records what you have agreed about what will happen to your partner or relative's body and organs once the coroner's duties are complete. It also gives you an opportunity to donate tissue or organs from the body for medical education or research, if you wish to do so.

Please read the accompanying information leaflet very carefully before completing the form. A member of the hospital staff or the coroner's officer will explain the content of this form and the leaflet and try to answer any questions you may have. The form is divided into several sections. You should read each one carefully and discuss it with the hospital staff or coroner's officer before completing it.

**Section 1** – Statement of understanding that the coroner has legal power to order a full post mortem, including removal of body fluids and tissues for laboratory examination, and the taking of X-rays and other images.

**Section 2** – Agreement to use of tissue and fluid samples taken during the post mortem in medical research.

**Section 3a** – Agreement that whole organs retained after the post mortem be donated for medical research, education or audit.

**Section 3b** – Agreement on how any remaining tissue and organs be disposed of following the post mortem.

**Section 4** – Any specific requests or conditions.

If you are satisfied with the information recorded, sign section 5. The member of hospital staff or the coroner's officer who has discussed the examination with you will sign section 6 and give you a copy of the complete form.

**You have the right to change your mind within a short time limit agreed with the hospital.**

If you wish to ask further questions about the post mortem examination, make changes to what you have recorded on this consent form, or withdraw your consent, please telephone

(contact name and number) as soon as possible and not later than  
 (date/time). You will be given a copy of the amended form.

## 1 Post mortem examination on an adult, ordered by the coroner

## 1. Post mortem examination

**I understand** that the coroner has ordered that a post mortem examination should be carried out to establish cause of death of [REDACTED] (name).

**I understand** that this is a legal requirement and my agreement is not needed.

### Note

During the examination, samples of body fluids and tissues may be removed for laboratory examination. Tissue samples are made into blocks and slides for examination with a microscope. Any tissue remaining from this process (residual tissue) will usually be disposed of. Blocks and slides are kept indefinitely as part of the medical record or in case they are needed in the future for further tests relating to the cause of death or your partner or relative's treatment. They may also be used for medical education and audit.

During the examination, photographs, X-rays or other images may be taken. They are usually kept indefinitely as part of the medical record. They may also be used for medical education, audit, or research, in which case information that might allow your partner or relative to be identified would be removed.

## 2. Agreement to donation of tissue and fluid samples for use in medical research

If you agree, tissue and/or fluid samples taken at the time of the post mortem examination may also be used later in ethically-approved research. This may benefit other patients in the future.

**Please choose one of the following options:**

☐ **I agree** to tissue or fluid samples already taken as part of the post mortem examination being used for medical research.

☐ **I agree** to tissue or fluid samples already taken as part of the post mortem examination being used for medical research EXCEPT for certain types of medical research, as described here:

[REDACTED]

☐ **I object** to any tissue or fluid samples being used for medical research.

**NB: No tissue may be taken primarily for use in research without completion of a specific, separate consent form for that purpose.**

### 3. Retention of tissue and organs (other than for blocks and slides) for more detailed examination

Only complete this section (parts 3a and 3b) if it is necessary in your case to retain whole organs and tissue. The coroner's officer will tell you if this is required. Otherwise, go straight to question 4.

Only a certain amount of information can be obtained at the time of the post mortem examination and in some cases it may be necessary to retain tissue and organs for further, more detailed examination, in addition to the samples described in section 1. This may be needed to find the precise cause or circumstances of death. If you wish to know, you can ask to be told if any tissue or whole organs are retained after the post mortem examination.

#### 3a Donation of whole organs for medical education, research or audit

If you agree, whole organs removed and retained after the post mortem examination may be kept for future use in medical education, audit and/or ethically-approved research.

**Please choose one of the following options:**

- ☐ **I agree** to any whole organs which have been removed as part of the post mortem examination being kept for medical education, research or audit.
- ☐ **I agree** to any whole organs which have been removed as part of the post mortem examination, EXCEPT the following organs   
 being kept for medical education, research or audit.
- ☐ **I agree** to any whole organs which have been removed as part of the post mortem examination being kept for certain types of medical education, research or audit, EXCEPT for certain types of medical education, research or audit, as described here:
- ☐ **I object** to any whole organs being kept for medical education, research or audit.

#### 3b Disposal of tissues and whole organs

After further investigations are complete, what would you like to happen to any remaining tissue or organs (other than those which have been made into tissue blocks and slides for microscopic examination)?

**Please choose one of the following options:**

- ☐ **Return to the body:** I would like the tissue and organs to be returned to the body. I understand that they may not be returned to their original position in the body. I understand that this may delay the funeral.
- ☐ **Hospital disposal:** I would like the hospital to arrange for disposal of the organs and tissue.
- ☐ **Return to self/funeral director:** I would like the organs and tissue to be returned to me/the funeral director (*please delete as appropriate*) to arrange lawful disposal. I understand that this may mean that I need to arrange a separate service after the funeral.

#### 4. Other requests or conditions

Do you have any particular requests or concerns? If so, please note them here.

#### 5. Signature of next-of-kin

Name  (PLEASE PRINT)

Signature

Relationship to the deceased person: parent/husband/wife/partner/brother/sister/other

(please specify)

Address

in the presence of

Name of  
witness\*

Signature

Address

\*Witness may be anyone who is not a member of your family, e.g. friend, neighbour or member of hospital staff.

## 6. Signature of member of staff completing record

### I confirm that

☐ I have explained to the person completing this form the procedures involved and the reasons for the investigations ordered by the coroner.

☐ I have explained what tissue samples, blocks and slides are.

☐ I have discussed any special requirements of the case, as follows:

☐ I have checked that all parts of the form have been completed.

☐ I have provided the following information leaflet(s)

☐ I have/have not discussed the case with a pathologist

(Please name pathologist:  )

### Signature of coroner's officer/doctor/nurse/other member of staff completing record

Name:

Job title/position

Telephone contact  
number

Bleep

## Notes

1. One copy of the completed form should be given to the next-of-kin or person completing the form, one copy retained by the coroner, one placed in the patient medical record and/or held by the pathology department or mortuary. (Local procedures to be followed.)
2. If any procedures or uses of material are envisaged which are not pre-printed on this form, a full explanation must be given and noted in section 4. Similarly, if the pre-printed options do not match the reasonable wishes of the family (e.g. sections 3a and 3b for certain research only to be done on certain organs only), please record any further, preferred options in section 4.
3. If consent for the donation of tissue or organs is subsequently withdrawn, all relevant sections of each page of each copy of the form should be clearly struck through. The person taking the withdrawal should also sign and date the form, and note any action taken to inform the mortuary (the date and time and name of member of mortuary staff informed).



# Post mortem examination on a baby or child, ordered by the coroner

Baby or child's surname/family name	Consultant (or other responsible health professional)
<input type="text"/>	<input type="text"/>
Other names (if given)	
<input type="text"/>	
Hospital unit number	NHS number
<input type="text"/>	<input type="text"/>
Date of birth	Male/female
<input type="text"/>	<input type="text"/>
Any other relevant details (e.g. preferred language of next-of-kin, religion)	
<input type="text"/>	

This form and the information leaflet that goes with it should help you understand the procedures involved in the post mortem examination which has been ordered by the coroner. It also officially records what you have agreed about what will happen to your baby or child's body and organs once the coroner's duties are complete. It also gives you an opportunity to donate tissue or organs from your baby or child's body for medical education or research, if you wish to do so.

Please read the accompanying information leaflet very carefully before completing the form. A member of the hospital staff or the coroner's officer will explain the content of this form and the leaflet and try to answer any questions you may have. The form is divided into several sections. You should read each one carefully and discuss it with the hospital staff or coroner's officer before completing it.

**Section 1** – Statement of understanding that the coroner has legal power to order a full post mortem, including removal of body fluids and tissues for laboratory examination, genetic testing and the taking of X-rays and other images.

**Section 2** – Agreement to use of tissue and fluid samples taken during the post mortem in medical research.

**Section 3a** – Agreement that whole organs retained after the post mortem be donated for medical research, education or audit.

**Section 3b** – Agreement on how any remaining tissue and organs be disposed of following the post mortem.

**Section 4** – Any specific requests or concerns.

If you are satisfied with the information recorded, sign section 5. The member of hospital staff or the coroner's officer who has discussed the examination with you will sign section 6 and give you a copy of the complete form.

**You have the right to change your mind within a short time limit agreed with the hospital.** If you wish to ask further questions about the post mortem examination, make changes to what you have recorded on this consent form, or withdraw your consent, please telephone

(contact name and number) as soon as possible and not later than  
 (date/time). You will be given a copy of the amended form.

## 1. Post mortem examination

I am/We are the parent(s) or legal guardian(s) of [REDACTED] (baby/child's name, if given). **I/We understand** that the coroner has ordered that a post mortem examination be carried out on my/our baby or child, and that this is a legal requirement for which my/our agreement is not needed.

### Note

During the examination, samples of your baby or child's body fluids and tissues may be removed for laboratory examination. Tissue samples are made into blocks and slides for examination with a microscope. Any tissue remaining after this process (residual tissue) will usually be disposed of. Blocks and slides are kept indefinitely as part of the medical record or in case they are needed in the future for further tests relating to your baby or child's cause of death or illness, including genetic testing. They may also be used for medical education and audit.

During the examination, photographs, X-rays or other images may be taken. They are usually kept indefinitely as part of the medical record. They may also be used for medical research, education or audit, in which case information that might allow your baby or child to be identified would be removed.

## 2. Agreement to donation of tissue samples for use in medical research

If you agree, the tissue and/or fluid samples taken at the time of the post mortem examination to diagnose your baby or child's illness and cause of death may be used later in ethically-approved medical research. This may benefit other patients in the future.

### Please choose one of the following options:

☐ **I agree** to tissue or fluid samples already taken as part of the post mortem examination being used for medical research.

☐ **I agree** to tissue or fluid samples already taken as part of the post mortem examination being used in medical research EXCEPT for certain types of medical research, as described here:

[REDACTED]

☐ **I object** to any tissue or fluid samples being used for medical research.

**NB: No tissue may be taken primarily for use in research without completion of a specific, separate consent form for that purpose.**

### 3. Retention of tissue and whole organs (other than for blocks and slides) for more detailed examination

*Only complete this section (parts 3a and 3b) if it is necessary in your case to retain whole organs and tissue. The coroner's officer will tell you if this is required. Otherwise, go straight to question 4.*

Only a certain amount of information can be obtained at the time of the post mortem examination, and in some cases the pathologist may remove and retain some tissue and/or whole organs for further, more detailed examination, in addition to the samples described in section 1. This may be needed to find the precise cause of death. If you wish to know, you can ask to be told if any tissues or organs are kept after the post mortem examination.

#### **3a Donation of whole organs for medical research, education or audit**

If you agree, any whole organs removed and retained after your baby or child's post mortem examination may be kept for future use in medical education, audit or ethically-approved research.

**Please choose one of the following options:**

- ☐ **I agree** to any whole organs removed as part of the post mortem examination being kept for medical research, education or audit.
- ☐ **I agree** to any whole organs removed as part of the post mortem examination, EXCEPT the following

being kept for medical research, education or audit.

- ☐ **I agree** to any whole organs removed as part of the post mortem examination being kept for medical research, education or audit EXCEPT for certain types of medical research, education or audit, as described here:

- ☐ **I object** to any whole organs removed as part of the post mortem being kept for medical research, education or audit.

#### **3b Disposal of tissue and whole organs**

After further investigations are complete, what would you like to happen to any remaining tissue and whole organs (other than those which have been made into blocks and slides for microscopic examination)?

**Please choose one of the following options:**

- ☐ **Return to the body:** I would like my baby or child's organs and tissue to be returned to the body. I understand that they may not be returned to their original position in the body. I understand that this may delay the funeral.
- ☐ **Hospital disposal:** I would like the hospital to arrange for disposal of my baby or child's organs and tissue.
- ☐ **Return to self/funeral director:** I would like my baby or child's organs and tissue to be returned to me/the funeral director (*please delete as appropriate*) to arrange lawful disposal. I understand that this may mean that I need to arrange a separate service after the funeral.

#### 4. Other requests or concerns

Do you have any particular requests or concerns? If so, please note them here.

#### 5. Signature of parent(s) or other legal guardian(s)

Name(s)  (PLEASE PRINT)

Signature(s)

Address(es)

in the presence of

Name of  
witness\*

Signature

Address

\*Witness may be anyone who is not a member of your family, e.g. friend, neighbour or member of hospital staff.

## 6. Signature of member of staff seeking consent

### I confirm that:

- ☐ I have explained to the parent(s) or legal guardian(s) the procedures involved and the reasons for the investigations ordered by the coroner.
- ☐ I have explained what tissue samples, blocks and slides are.
- ☐ I have discussed any special requirements of the case, as follows:

- ☐ I have checked that all parts of the form have been completed.
- ☐ I have provided the following information leaflet(s)

- ☐ I have/have not discussed the case with a pathologist

(Please name  
pathologist:

)

### Signature of coroner's officer/doctor/nurse/other member of staff seeking consent

Name:

Job title/position

Telephone  
contact number

Bleep

## Notes

1. One copy of the completed form should be given to the child's parent or legal guardian, one copy retained by the coroner, one placed in the patient medical record and/or held by the pathology department or mortuary. (Local procedures to be followed.)
2. If any other procedures or uses of material are envisaged, a full explanation must be given and noted in section 4. Similarly, if the pre-printed options do not match the reasonable wishes of the family (e.g. sections 3a and 3b for certain research only to be done on certain organs only), please record any further, preferred options in section 4.
3. If consent for the use of tissue or organs is subsequently withdrawn, all relevant sections of each page of each copy of the form should be clearly struck through. The person taking the withdrawal should also sign and date the form clearly, and note any action taken to inform the mortuary (the date and time and name of member of mortuary staff informed).









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