

CHILD 12 OR OVER AUTHORISATION FORM

Guidance for Clinical Staff

Introduction

This document is intended as a quick guide to the authorisation form introduced as part of the Human Tissue (Scotland) Act 2006 and with reference to NHS circular HDL (2006)46 published 20th July 2006.

The term "authorisation" has been chosen in Scotland rather than consent which applies to surgical operations and which is the term used in England and Wales for post mortem examinations, for the following reasons: parents may choose to have as much or as little information as they wish about a post mortem procedure and in this context consent would not be an appropriate term. Authorisation implies more control over the decision whether to proceed with a post mortem or not. It is recommended that senior medical staff obtain authorisation. This additional authorisation form for a child 12 years or over has been designed in order to adhere to the Human Tissue (Scotland) Act 2006.

Please read the information leaflets before speaking to parents, and if there is any item that you don't understand, please seek advice.

Information pack: All forms and leaflets are intended to be kept in one place and for convenience a special pack has been designed. (The pack and folder cover may however not be available on the 1st of September 2006).

Some parents may wish for no information but should still sign the authorisation form. Others may require simple reassurance and this should be provided by the basic information leaflet. Some parents may require more information which should be answered in the advanced information leaflet while other parents may require detailed explanation which can be answered by appropriately trained staff. While parents will still need to sign the authorisation form, the pack is designed so that they may choose to read all or none of the information leaflets.

The pack is designed with a brief summary of important information on the inside cover, notes to assist those obtaining consent on the back of the inside cover and contact details for national support groups on the back cover. There is room within the information pack for any local information leaflets that might be appropriate.

Authorisation form:

Identification:

You can use addressograph labels in the space provided but please make sure you remember to put a label on each copy of the triplicate forms.

If you do not use a label, then please write: the **Child's First Name, Surname, Date of Birth, Date of Death and Unit/CHI Number** of the deceased.

| |
|---------------|
| Child's name |
| Date of birth |
| Date of death |
| Unit no. |
| CHI no. |

Parent or Nominated Representative :

Please indicate whether the authorising person is a parent or a nominated representative of the child, and write the name of the child.

The child's wishes if previously expressed are paramount and the next sentence is required to ensure there were no instructions left by the child. This can be left without modification if there were no wishes left by the child.

| | |
|--|--|
| <input type="checkbox"/> I/We have parental rights and responsibilities for: | <input type="checkbox"/> I am/We are the nominated representative(s) of: |
| <i>(If acting as a nominated representative): I confirm I am an adult (16 years of age or over).</i> | |
| I/We have no actual knowledge that the above named child was unwilling (a) for a post-mortem examination to be carried out and (b) for organs to be removed, retained or used for any of the purposes of audit, education, training or research which are authorised by virtue of this form. | |

| |
|---|
| Section 1A. Authorisation of a full post-mortem examination |
| <input type="checkbox"/> I/We authorise the carrying out of a full post-mortem examination on the above-named child, which involves internal examination of the body and the keeping of small tissue samples as blocks and glass slides, samples of blood and bodily fluids, and may involve taking photographs, X-rays and scans. These will be kept as part of the medical record and may be used for audit, education, training or research. |
| OR |
| Section 1B. Authorisation of a limited post-mortem examination |
| <input type="checkbox"/> I/We authorise the carrying out of a limited post-mortem examination on the above-named child, which may involve keeping small tissue samples as blocks and glass slides, samples of blood and bodily fluids, and may involve taking photographs, X-rays and scans. These will be kept as part of the medical record and may be used for audit, education, training or research. |
| Please say what you authorise to be examined: |
| <input type="checkbox"/> head <input type="checkbox"/> chest <input type="checkbox"/> abdomen |
| <input type="checkbox"/> other (please state what is to be examined) |
| OR |
| Section 1C. Authorisation of an external post-mortem examination |
| <input type="checkbox"/> I/We authorise the carrying out of an external post-mortem examination on the above-named child, which may involve taking: |
| <input type="checkbox"/> photographs <input type="checkbox"/> X-rays |
| <input type="checkbox"/> scans <input type="checkbox"/> small skin or muscle samples |

Section 1:

The form is divided into sections for ease of use and Section 1 is intended to indicate either a full examination or a limited internal examination.

(A) If a full examination is authorised, tissue samples will be made into tissue blocks and glass slides for examination and subsequent storage and these will then form part of the medical record.

(B) If limited internal examination is authorised, this can either be by region (head, chest, abdomen – tick box) or be more specific (eg, heart and lungs). Please remember that other organs may need to be removed but not retained in the process of examining a specific organ or organs. If an examination is severely restricted, the pathologist may advise that it is not appropriate to proceed. Consider what the clinical questions are, and if you are unsure, please contact the Pathology Department for advice.

N.B. If Head, Chest and Abdomen are all ticked then that is virtually equivalent to a full post mortem examination.

(C) It seems unlikely that this would be a useful option following the death of a 12 year old child.

Section 2:

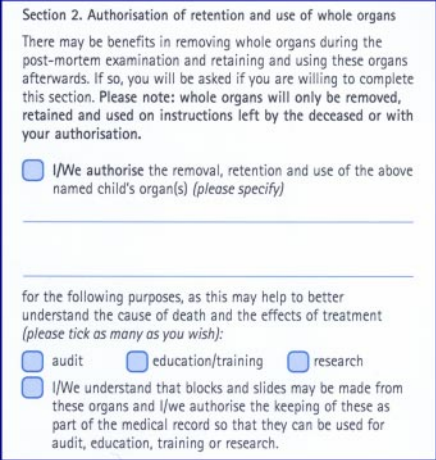
As currently drafted, the authorisation form does not make clear that the primary intention of retaining an organ is usually for diagnosis. One interpretation of the form is that organs may be retained for a short period under section 1. Another interpretation is that the form does not make clear that relatives are authorising retention of an organ for diagnosis. Most pathologists would be unhappy to retain an organ for any period of time unless there is explicit permission from the relatives. Therefore it is recommended that if an organ is to be retained for diagnosis for any length of time that the word "diagnosis" is added to the form in this section.

This section deals with organ retention and if there is no clinical requirement for organ retention, then this section can be left blank, (it may be useful to put a line through this section if not relevant). The heart and brain are the two organs that most commonly require to be retained. This may often be the case in diffuse neurological disease including neurodegenerative disorders, brain tumours or after neurosurgery. It may be advantageous to retain the heart if there is a history of cardiac arrhythmia, congenital heart disease or sudden unexpected cardiac death. You are advised to discuss this with the pathology department before speaking to the parents.

It is possible that there may be unexpected findings during a post mortem examination that indicate the need to retain an organ. In that case, the clinician obtaining consent will be contacted with a view to obtaining the parent's authorisation. However, this is an unlikely event.

N.B. Please tick the initial box for organ retention then indicate which organ(s) are to be retained. It is important that if an organ is retained, tissue blocks and slides are made as part of the medical record. If the parent is unwilling for this to happen, speak to the Pathology Department.

The usual purpose in retaining an organ is to make a **clinical diagnosis**, the boxes here are **additional uses** that can be made of a retained organ. Sometimes individuals with a specific neurological condition will wish to donate their brain for research.



Section 2. Authorisation of retention and use of whole organs

There may be benefits in removing whole organs during the post-mortem examination and retaining and using these organs afterwards. If so, you will be asked if you are willing to complete this section. Please note: whole organs will only be removed, retained and used on instructions left by the deceased or with your authorisation.

I/We authorise the removal, retention and use of the above named child's organ(s) (please specify)

for the following purposes, as this may help to better understand the cause of death and the effects of treatment (please tick as many as you wish):

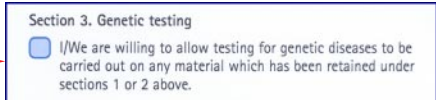
audit education/training research

I/We understand that blocks and slides may be made from these organs and I/we authorise the keeping of these as part of the medical record so that they can be used for audit, education, training or research.

Section 3: Genetic testing:

This is included because the Human Tissue Act (2004), which mainly applies to the rest of the UK, applies to Scotland in respect of DNA analysis. (See Human Tissue Authority Code of Practice – Consent: Code 1). It is an offence under Section 45 of the Human Tissue Act (2004) to have any bodily material from a human body with intent to analyse it in any way without qualifying consent, subject to certain exceptions. The offence does not apply if the results of analysis are to be used for "excepted purposes". The following are excepted purposes:- 1) Medical diagnosis or treatment of that person, 2) Procurator Fiscal purposes, 3) Prevention or detection of crime or prosecution, 4) National security, 5) Court/Tribunal order or direction.

It is parently unlikely that a post mortem in an child aged 12 years or over will require genetic analysis. However, if there is the possibility of an underlying syndrome with known DNA mutation, then discussion with the parents should indicate that genetic testing may be necessary to make the diagnosis. Please note that in complex cases where there are significant implications for other members of the family, then further advice should be sought. (For further information, see Human Tissue Authority Code of Practice 1, page 26-28).

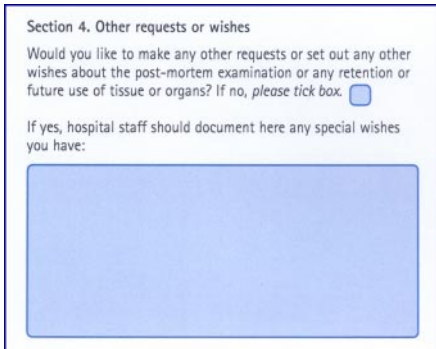


Section 3. Genetic testing

I/We are willing to allow testing for genetic diseases to be carried out on any material which has been retained under sections 1 or 2 above.

Section 4: Other requests or conditions:

There may be special funeral arrangements or religious practices that need to be observed and, if so, please indicate these here. If there are **no** special requirements, then please indicate in the appropriate box.



Section 4. Other requests or wishes

Would you like to make any other requests or set out any other wishes about the post-mortem examination or any retention or future use of tissue or organs? If no, please tick box.

If yes, hospital staff should document here any special wishes you have:

To be completed by member of hospital staff who has discussed authorisation

I confirm that:

- I have asked if the deceased had authorised the matters covered by this form.
- I have attached a copy of any information left by the deceased or a note of any objections he or she is believed to have had.
- I have offered information to the nominated representative person with parental rights and responsibilities about the procedures involved and the reasons for investigations requested. I have offered to explain any procedures and options available in the level of detail that the nominated representative/person with parental rights and responsibilities wish and have given any explanations asked for.
- (If only one person with parental rights and responsibilities is present): I have asked whether there is likely to be any objection to a hospital post-mortem examination from anyone else with parental rights and responsibilities.
- I have explained that unless the procedures authorised have already taken place, the authorisation given by the nominated representative(s)/person with parental rights and responsibilities can be withdrawn at any time, but that withdrawal must be in writing and witnessed by two witnesses. An amended version of this form would then be passed to the person who would otherwise have undertaken the post-mortem examination.

Written information given:

Basic leaflet Advanced leaflet None

(To be completed where whole organs were removed under section 1:)

I have discussed the options for disposal of whole organs which have not been retained under section 2, and have noted the following wishes:

- the organs should be returned to the body after the examination. I have explained that this may delay the funeral.
- the hospital should arrange for respectful disposal of the organs.
- the funeral director should collect and arrange for respectful disposal of the organs.

Completion by Member of Staff:

The person who is assisting the parents in completing this form needs to indicate here that certain points have been covered in the authorisation process.

N.B. Please note all these boxes **must be** ticked except perhaps the box relating to the instructions left by the deceased.

Please indicate what written information leaflet has been given to the parents (if any).

Please note there is an error in the early drafts of this form which refer incorrectly to section 1 and have not been retained under section 2. Please delete "not".

If any organs were retained as authorised by **Section 2** then consideration needs to be given to the disposal options that the parents have, for example it may be possible to return the organ to the body before the funeral: (Please indicate **ONE** option only.)

a) Returned to the body – If the parents wish the organ to be returned to the body before the funeral, then please speak to the pathology department about the timescale.

b) Hospital disposal – If the parents wish the Health Board to take responsibility for disposal of the organ, then please indicate here. Different Health Boards will have different procedures for the disposal of organs retained after post mortem examination. Contact the local or regional Pathology Department for advice.

c) Collection by Funeral Director - If the parents wish to arrange their own cremation or burial at a later date, then this option should be indicated.

N.B. This section does not need to be completed if no organ is retained.

Signatures:

Please sign indicating that you have obtained authorisation from the parents giving your name and further details as requested.

The signature of the person giving authorisation is also required with their full name in capital letters. Ideally both parents would sign the form, but this may not always be practical

There needs to be a further two witnesses to the authorisation process, and these can be members of staff and/or other relatives but not a second nominated representative.

NOTES:

1) The authorisation form is in triplicate with the top copy to be given to the parents, one copy to be retained in the patient's case notes and one copy to be sent to the pathologist who will perform the post mortem examination.

N.B. Please make sure the copy for the Pathology Department is readable.

2) If the authorisation for post mortem examination is withdrawn, then all copies of the form should be amended with details of the change of authorisation and the date and time the change was made. The pathology department should be contacted **without delay** in order to indicate that authorisation has been withdrawn.

N.B. Please note post mortem examinations may be carried out within 24 hours.

3) If any extra tissue is to be taken at post mortem examination for use in research, specific authorisation **MUST** be obtained using a separate form. The research study should have a consent form agreed by a Research Ethics Committee that needs to be signed by a parent. This specific authorisation is the responsibility of the research group and not the pathology department.

To be completed by person with parental rights and responsibilities/ nominated representative(s)

I am/We are the deceased's nominated representative(s) or I have parental rights and responsibilities for _____

The post-mortem examination has been explained to me and I feel that I have been provided with enough information to give the authorisation set out in this form.

Signature _____

Name (block capitals): _____

Date _____

Relationship to the child: (please tick box)

Mother Father

Guardian Nominated representative

Contact details _____

Signature of person witnessing authorisation
(Note: there must be two witnesses to authorisation. Both are required to witness the content of the form and the signature of the person providing authorisation. Both witnesses must be present at the same time, and both must be 16 years of age or over. A person who is a nominated representative of the deceased child cannot act as a witness to authorisation by another nominated representative.)

Witness One:

Signature _____

Name (block capitals) _____

Date _____

Job title* _____

Witness Two:

Signature _____

Name (block capitals) _____

Date _____

Job title* _____

* If member of hospital staff