

# BABY OR CHILD UNDER 12 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 20<sup>th</sup> 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 and it is likely in a Neonatal Unit that this will be consultant staff, in an Obstetric Unit this is likely to be consultant or middle grade staff.

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 1<sup>st</sup> 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.

Baby or child's name _____
Date of birth _____
Date of death _____
Unit no. _____
CHI no. _____

If you do not use a label, then please write: the **Baby or Child's Name, Date of Birth, Date of Death (or Delivery if stillborn) and Unit/CHI Number** of the child. For a stillbirth or fetus with no name, please use the Mother's name, and put Mother in brackets.

#### Parental rights and responsibilities:

If the baby is a stillbirth or fetus without a name, then please put "Fetus/Stillbirth of..." and indicate the Mother's name. Please indicate the relationship of the parent/guardian at the end of the authorisation form

<input type="checkbox"/> I have parental rights and responsibilities for (name of baby or child): _____
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Section 1A. Authorisation of a full post-mortem examination

I authorise the carrying out of a full post-mortem examination on my baby or child, which involves internal examination of the body, the keeping of small tissue samples as blocks and 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

I authorise the carrying out of a limited post-mortem examination on my baby or child, which involves the keeping of small tissue samples as blocks and 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:

head     chest     abdomen

other (please state what is to be examined)

OR

Section 1C. Authorisation of an external post-mortem examination

I authorise the carrying out of an external post-mortem examination on my baby or child, which may involve taking:

photographs     X-rays

scans     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 or external examination only.

(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) For a fetus or stillbirth, there is value in an external examination: information such as growth parameters or external abnormality will be recorded and will prove useful. Clinical photographs provide a permanent record of any dysmorphism. The small skin and muscle samples are intended for genetic analysis or other tests.

Please indicate **External Examination** and then the individual options that are authorised. Scans are unlikely, photographs and x-rays are the minimum that should be authorised. Please delete skin and muscle if not appropriate.

## 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 congenital abnormality, or where there has been surgery. Organ retention will vary depending on clinical and pathological practice locally and you should know your local practice. Please contact the pathology department before speaking to the parents if you are unsure.

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 relative 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.

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 with your authorisation.

I authorise the removal, retention and use of my baby's or child's organ(s) (please specify)

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

audit     education/training     research

I understand that blocks and slides may be made from these organs and I 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.

Post mortem examinations on fetuses and stillbirths not uncommonly require genetic testing for diagnosis, usually chromosome analysis, but also PCR with specific probes, and occasionally DNA analysis. Where the material is taken with the purpose of making a diagnosis, this would be an “excepted” purpose.

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 Practice1, 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.

It may be that parents wish their child to wear specific clothes or to have a cuddly toy for the funeral, please note this information here. If there are **no** special requirements, then please indicate this 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 offered information to the person with parental rights and responsibilities about the procedures involved and the reasons for the investigation requested. I have offered to explain any procedures and options available in the level of detail that the person with parental rights and responsibilities wishes 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 person with parental rights and responsibilities can be withdrawn at any time, but that withdrawal must be in writing and witnessed by one witness. 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. If only one parent is present and authorising the post mortem examination, then please indicate that she/he does not know of any objection by the other parent.

N.B. Please note all three boxes **must be** ticked.

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. Please indicate the relationship of the authoriser to the baby or child. Contact details may be useful at a later date.

There needs to be a further two witnesses to the authorisation process, and these can be members of staff and/or other relatives.

## 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

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.

Name (block capitals): \_\_\_\_\_

Signature \_\_\_\_\_

Name (block capitals) \_\_\_\_\_

Date \_\_\_\_\_

Relationship to the child: (please tick box)

Mother  Father  Guardian

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.)

Witness One:

Signature \_\_\_\_\_

Name (block capitals) \_\_\_\_\_

\_\_\_\_\_

Date \_\_\_\_\_

Job title\* \_\_\_\_\_

Witness Two:

Signature \_\_\_\_\_

Name (block capitals) \_\_\_\_\_

\_\_\_\_\_

Date \_\_\_\_\_

Job title\* \_\_\_\_\_