

RETENTION OF ORGANS FOLLOWING POST MORTEM

The Consultant Staff of the Department of Pathology have compiled the following interim response to Dr Campbell's letter of 25 January. Final details not yet available will be fully documented by 28 February 2001.

POST MORTEM CONSENT

Consent for 'Routine' Adult Hospital Autopsies

The hospital is in the course of introducing the 'new' permission format specified by the Royal College of Pathologists (Document 'A' enclosed). This has been agreed by the Medical Committee and the Hospital Council, and the printed forms are currently being circulated to consultant staff. A comprehensive training exercise will lead to the uniform use of the new form. Guidance notes recommended by the Royal College have also been printed and are being circulated for use (Document 'B' enclosed).

The 'old' consent form is much less complex (Document 'C' enclosed). This refers to 'tissue' rather than specific 'organs', a wording which has led to the current problems. This form was introduced about 16 years ago and has been used until now. No specific guidance notes were produced by the hospital to accompany this form. Since the publication of the guidelines on organ retention by the Royal College of Pathologists in 2000, Pathologists in this Hospital have not retained organs from routine hospital autopsies on adults, unless specifically informed and signed permission is added to the existing wording of the 'old' form (see Neuropathology, below)

The autopsy consent form from the period prior to 16 years ago made no reference to either organ or tissue retention (Document D, enclosed).

Consent for Neuropathology Autopsies

Clinicians in neurology and neurosurgery are fully aware of the need to retain the brain for a full and accurate diagnosis and they make this clear to relatives when consent is being requested. If consent is granted, the fact is formally recorded as an addition to the 'old' consent form and is signed and witnessed. The 'new' consent form will shortly be introduced for neuropathology cases, as elsewhere in the Hospital.

Consent for Paediatric Autopsies

Since early 2000, the paediatric the consent form (Document E enclosed) has included specific sections regarding organ retention and subsequent disposal. It is accompanied by the blue Autopsy Information Booklet (Document F enclosed).

From 1993 - 2000, the consent form used was Document G, but without the sections relating to organ retention. This form was accompanied by the yellow Autopsy Information Booklet. Prior to 1993, there was no information booklet for parents and the consent form, for the majority of cases, was the same as that used throughout the Hospital.

In 1993 the yellow booklet (Document H) was introduced, as the existing paperwork was felt to be outdated and inadequate. At this time, the paediatric pathologists were trying to introduce the idea that all fetuses and babies, irrespective of size or gestational age, deserved the same respect and care and so arranged disposal of bodies by cremation at Roselawn Crematorium. The 1993 consent form covered not only consent for autopsy, but also parental wishes regarding disposal of the body and was required to be completed for every baby dying or born dead.

Procedures for Seeking Consent, by 'Bedside' Doctors

Consent for a hospital post mortem is obtained by a doctor who is a member of the medical team who has been looking after the patient. The clinician will speak to the next-of-kin and preferably, other members of the family circle to describe the circumstances around the death and to explain the reasons why a post mortem is being requested. They are then asked to sign the hospital consent form. At times, a hospital post mortem confined to one organ system may be requested and agreed to and this will be indicated in the consent form. Members of the clinical team will also endeavour to answer practical questions around the post mortem, such as when the body will be available for collection by the undertakers.

TOTAL NUMBERS OF POST MORTEMS

Table 1 details all post mortems carried out from 1970 to 2000. The overall total is 21,084. This is broken down to show separate totals for adult, paediatric and neuropathology post mortems.

practice. The audit of the quality of care is assisted by such studies and opportunities are provided for the improvement of clinical care in future cases of a similar sort.

In some post mortems, the presence or suspicion of infective disease presents a serious potential hazard to morticians and pathologists. Examples include HIV, tuberculosis and hepatitis. In such cases, unfixed, fresh organs cannot be dissected. Organs must therefore be preserved in fixatives to inactivate microorganisms before dissection and further study can be undertaken.

Teaching and Training

Organ pathology has always been an important component of medical education and every doctor trained in Belfast has benefited from our collection, gathered over the last century. Although the curriculum nowadays has less time for such studies, the demonstration of 'unfixed' diseased organs from current post mortems was a regular activity over many years. These organs could therefore not be returned to the body before burial. Similarly, the review of diseased organs by junior pathologists in training, under consultant tuition, was a regular occurrence in the Department. In the last fifteen years, the expansion of the scientific content of specialist training has led to a decline in such activity, but the result has been a perceptible diminution in the experience which trainees have been able to acquire in the area of 'gross' organ pathology.

Research

Retained organs and tissues represent a vital resource for research into various types of disease. HIV and CJD are examples of diseases where knowledge has been gained largely through the study of organs and tissues retained at autopsy.

Paediatric Cases

Paediatric organs were retained at autopsy for detailed examination to ensure that an accurate diagnosis was made and that the appropriate genetic counselling was given to the family involved. Paediatric cardiologists, cardiac surgeons and pathologists studied the hearts together as a team and gained information which improved the diagnosis and treatment for infants born with similar conditions in future years.

Neuropathology Cases

Neuropathology is concerned with the diagnosis of a wide variety of diseases that primarily affect the nervous system, and also with those systemic diseases that can involve the nervous system. A detailed neuropathological autopsy including

Examination of the brain and the spinal cord after fixation is a vital component of current good practice in the investigation of diseases of the nervous system. Without this, for example, explanation of patients' death or neurological signs and symptoms may be compromised. Neuropathological autopsy also provides information on the audit of in-hospital diagnosis and treatment and for the investigation of nervous system diseases which may have genetic basis, with implications for other family members. Neuropathological material is also regularly used for teaching and training of undergraduate and postgraduate students.

This Hospital has a long tradition of research achievement in Neuropathology in areas such as demyelinating disorders, including multiple sclerosis, brain tumours, muscular dystrophy and the surveillance of dementias, including human spongiform encephalopathies and VCJD. This work has been supported by a number of grants at local, national and international level. There are a number of publications and presentations from these in peer-reviewed scientific journals and at national and international meetings. In addition, we regularly collaborate with other Neurosciences centres in the diagnosis of rare genetic and metabolic disorders. None of this valuable work would have been possible without the benefit of retained tissues.

ACCESS TO RETAINED MATERIAL

Specimens are held securely by the Department under the authority of the Consultant Staff responsible for specific areas of the service. Access for the purposes of clinicopathological consultation, teaching, training or research is controlled by the relevant Consultant, from whom permission for access would normally be requested personally or in writing. Absolute confidentiality is always maintained and published studies are based on anonymised data. Ethical Committee approval is sought as and when required.

OTHER ISSUES

Coroner's Post Mortems

Over the last 10 years, the Department has carried out studies on industrial dust disease of the lungs, mostly on tissues retained from Coroners' post mortems. Such investigations may assist relatives in obtaining compensation. The inventory will establish the extent of tissue retention in such cases; whole organs are rarely held. We recognise that retention, and the subsequent disposal of retained tissues, is subject to the Coroner's instructions, but procedures to establish the Coroner's wishes on disposal have not been clearly established in times past. Clear procedures are now in place, but there is a legacy of past practice which will require attention.

DRAFT

Paraffin Blocks and Slides

All post mortems carried out in this Department have involved the retention of small tissue samples (20 x 10 x 3 mm) in the form of wax blocks of fixed tissue, from which histological sections are cut for microscopic examination. This is an essential part of a full and accurate autopsy. These wax blocks and slides are a vital archive of unique value for retrospective studies of disease. The integrity of such material as a resource for the future should be respected.

CONCLUSION

The Consultant Staff of this Department dissociate themselves entirely from the abuses uncovered by the Alder Hey enquiry.

For the last 100 years, this Department has strived to provide an excellent pathology service to our colleagues and for our patients, through a comprehensive autopsy service, and through our much more extensive commitment to the diagnosis of disease in living patients. We acknowledge that our past practice is now seen to have been defective in relation to informed consent. We have now implemented our new guidelines and we will welcome legislation to clarify the issues raised by organ retention. We emphasise that all past retention of organs and tissue samples has been for the specific, ethical purposes of accurate diagnosis, teaching, training and research.

2 February 2001

D

R.V.H.

POST MORTEM

The following information must be sent to the Mortuary Attendant for the information of the Professor of Pathology, and so that the "Registration of Deaths" Register can be completed:—

Name of Deceased.....

Provisional Diagnosis.....

Date of Death.....

Is a P.M. desired?.....

Has permission for a P.M. been obtained?.....

Date..... Signed.....

Resident Medical Officer

N.I.H.A.

Hospital	Surname and First Names	Hospital No.	
Ward or Dept.	Physician or Surgeon	Sex	Age

I hereby give consent to a Post Mortem examination being carried out on the body of

late of (address)

I am the nearest living relative of the deceased.

Signature

Address

Relationship to the deceased Date

POST MORTEM CONSENT FORM.

M.R.4

E

NORTHERN IRELAND REGIONAL PAEDIATRIC PATHOLOGY SERVICE

M1

**AUTOPSY AND BURIAL/CREMATION CONSENT FORM
FOR FETAL, STILLBIRTH AND NEONATAL DEATHS**



I,

am the mother of

who was born on

I confirm that the autopsy has been discussed with me and that I have been given the Autopsy Booklet.

(Please read all sections below, clearly cross out the parts which do not apply and sign the form):

Consent for Autopsy

1. I give consent for a full autopsy to be performed on my baby, which I understand will include examination of the brain
2. I give consent for only a limited autopsy to be performed on my baby – confined to head / chest / abdomen.
3. I give consent for an external post mortem examination only.
4. I do not wish an autopsy to be performed on my baby.

Retention of Organs

1. I give consent for the brain / heart to be retained for further examination if this is necessary to reach a diagnosis.
2. I do not give consent for the heart / brain to be retained but I understand that the information in the autopsy report may be less than complete.

Disposal of Retained Organs:

1. I wish the retained organ to be returned to me for burial/cremation when the autopsy report is complete.
2. I wish the hospital to arrange cremation of the retained organ when the autopsy report is complete.

Burial / Cremation

1. I wish to take my baby's body and I will arrange burial / cremation.
2. I wish the hospital to arrange cremation of my baby.

Signed Date

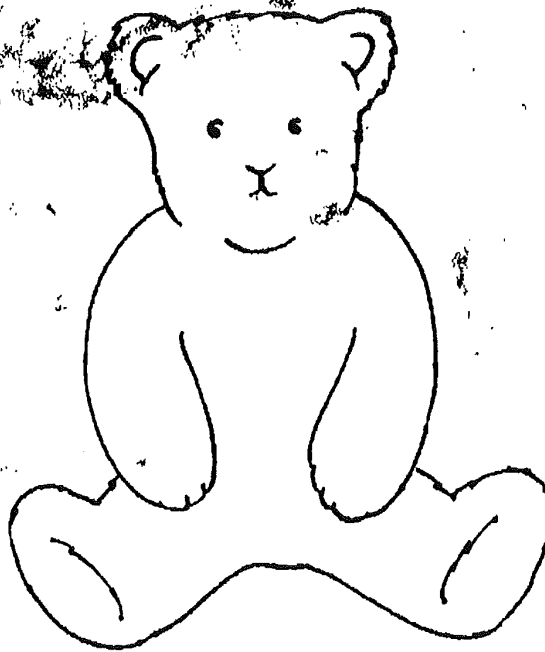
Witnessed by Status Date

ct cp.nirpps.jan.2000

F
1-4

Blue Booklet

Autopsy



Northern Ireland Regional Paediatric Pathology Service

F

The death of a baby at any stage in pregnancy or around the time of birth is a sad and traumatic event. It is a difficult task for nursing and medical staff to ask parents about an autopsy on the baby at this time, however it is important that parents understand why we ask for an autopsy and what it involves.

WHY IS AN AUTOPSY SO IMPORTANT?

It is important to find out if at all possible why your baby died, and the best way to do this is by an autopsy or post mortem examination. The autopsy may also give information as to whether your baby has a disease with genetic (hereditary) significance. Some conditions carry a risk as high as 1 in 2 of recurring in further pregnancies. This is important if you wish to have more children. It is also important information to give to the other members of your family. The more complete the medical information available to your family and their doctors the more accurate will be their assessment of the risks of other children being born with the same problem. Post mortem examinations also increase medical understanding of the diseases from which babies may die. In this way they improve the treatment and the chance of survival of other infants with similar problems.

WHAT IS AN AUTOPSY?

The autopsy is an examination of the organs of someone who has died. It is performed by a pathologist - a doctor with specialist training in this field. The pathologist removes the organs, examines them, takes thin samples of tissue (typically 1/4" thick) from them for processing and examination under a microscope or for further tests and then returns the organs to the body. Occasionally the pathologist may wish to retain an organ as

F

further examination would help to make the diagnosis. This is usually a brain or heart in which there are severe abnormalities. These abnormalities may not have been known about before autopsy. There is a separate section in the consent form for you to complete giving or withholding your permission for this to be done. The retained organ may be returned to you for burial/cremation. Alternatively the hospital can arrange cremation of the organ at Roselawn. The processed samples of tissue taken at autopsy are kept by the pathologist. These can be re-examined if new diagnostic techniques or fresh knowledge becomes available which might give a clearer explanation of the disease. Also they may later be valuable for education and training of doctors and midwives and for research into the causes of disease.

If you do not wish a full autopsy to be carried out on your baby you might consider giving consent for a limited examination confined to specified parts of the body. This limited post mortem may involve the pathologist examining the chest or the abdomen or the brain. In a small number of cases it is possible to make a diagnosis if the pathologist makes an external examination of the body, takes X-rays and does additional tests such as chromosomal analysis but does not open the body.

We want to assure you, the parents, that the body of your baby is treated with respect and dignity. Marks from the autopsy will not be visible when the baby is dressed and the face and hands are not involved in the post mortem examination. If you and your family or friends would like to see the body this is possible in the chapel at the mortuary either before or after the autopsy.

F

BURIAL/CREMATION

Irrespective of whether or not you consent to an autopsy on your baby you can decide to take the body and arrange burial/cremation through an undertaker of your choice or if you do not wish to do this the hospital can arrange for cremation of the body.

If the hospital is arranging the cremation, your baby will, like an adult, be cremated at the Belfast Crematorium, Roselawn. The ashes will be recovered and will be scattered in the Garden of Remembrance for Babies at Roselawn. In the case of a very small baby no ashes may be formed. Your baby's name will be recorded in the hospital's Book of Remembrance.

If you would like to arrange your baby's funeral through an undertaker of your choice, but feel that this would cost too much, there is a funeral grant available from the Social Fund for those receiving certain DHSS benefits. The ward staff will be able to tell you more about this grant.

G

FORM M1

AUTOPSY AND BURIAL/CREMATION FORM

I, am the mother
of who was delivered
on

(Please cross out the two sentences below which do not apply and
sign the form).

(1) I give consent for an autopsy to be performed on my baby.

or

(2) I do not wish an autopsy to be performed on my baby.

(3) I wish to take the body of my baby and I will arrange
burial/cremation.

or

(4) I wish the hospital to arrange the cremation of my baby.

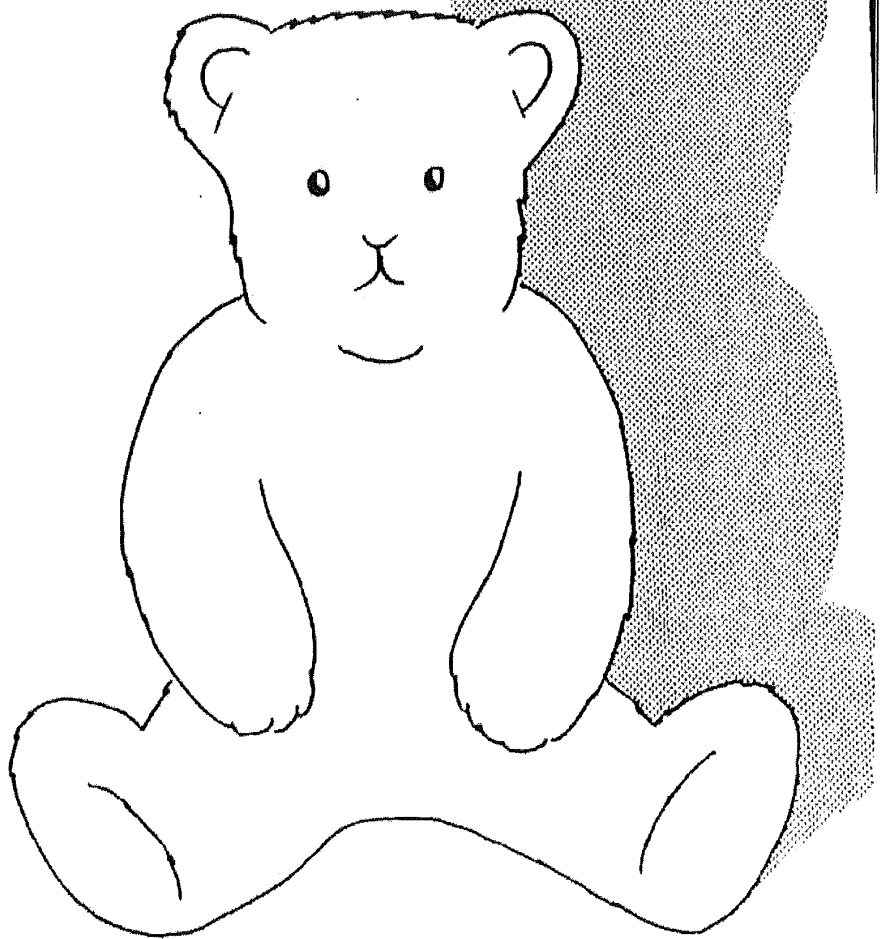
Signed Date

Witnessed by Date Status

H
1-4

YELLOW BOOKLET

Autopsy



NORTHERN IRELAND REGIONAL PAEDIATRIC PATHOLOGY SERVICE

H

The death of a baby at any stage in pregnancy or around the time of birth is a sad and traumatic event. It is a difficult task for nursing and medical staff to ask parents about an autopsy on the baby at this time. We feel it is important that parents understand why we ask for an autopsy and what it involves.

WHY IS AN AUTOPSY SO IMPORTANT?

It is important to find out if at all possible why your baby died, and the best way to do this is by an autopsy or post mortem examination. The autopsy may also give information as to whether your baby has a disease with genetic (hereditary) significance. This is important if you wish to have more children. It is also important information to give to the other members of your family. The more complete the medical information available to your family and their doctors the more accurate will be their assessment of the risks of other children being born with the same problem.

H

Post mortem examinations increase medical understanding of the diseases from which babies may die. In this way they improve the treatment and the chance of survival of other infants with similar problems.

WHAT IS AN AUTOPSY?

The autopsy is an examination of the organs of someone who has died. It is performed by a pathologist - a doctor with specialist training in this field. The pathologist removes the organs, examines them, takes thin slivers of tissue from them for examination under a microscope and then returns the remaining tissue to the body. We want to assure you, the parents, that the body of your baby is treated with respect and dignity. Marks from the autopsy will not be visible when the baby is dressed and the face and hands are not involved in the post mortem examination. If you and your family or friends would like to view the body this is possible in the chapel at the mortuary either before or after the autopsy.

H

BURIAL/CREMATION

Irrespective of whether or not you consent to an autopsy on your baby you can decide to take the body and arrange burial/cremation through an undertaker of your choice or if you do not wish to do this the hospital can arrange for cremation of the body.

If the hospital is arranging the cremation, your baby will be cremated at the Belfast Crematorium, Roselawn, and any ashes recovered will be scattered in the Garden of Remembrance. (In the case of a small baby no ashes will be formed). There is a Book of Remembrance in which your baby's name will be recorded.

If you would prefer to arrange your baby's funeral through an undertaker of your choice, but feel that this would cost too much, there is a funeral grant available from the Social Fund for those receiving certain DHSS benefits. The Ward staff will be able to tell you more about this grant.

4