



Aneurin Bevan University Health Board

Policy for the management of the disposal of non- viable fetal tissue, viable fetuses and stillbirth

N.B. Staff should be discouraged from printing this document. This is to avoid the risk of out of date printed versions of the document. The Intranet should be referred to for the current version of the document.

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Policy Statement

All non viable fetal tissue regardless of gestation will be managed with the dignity afforded to all human remains. All pregnancy tissue will be disposed of in accordance with the Human Tissue Authority Code of Practice.

• Introduction

Any pregnancy loss regardless of gestation is a painful and distressing event. The parents not only have to come to terms with the loss of their baby but they also have to ensure that both the law and their own needs are met. The time period referred to for the purpose of non-viable tissue is less than 24 weeks gestation where there was no evidence of life at delivery.

• Guiding Principles

The aim of this policy is to ensure that Aneurin Bevan University Health Board offers a consistent and sensitive approach to the disposal of non-viable fetal tissue. It is not a requirement in law to bury or cremate the tissue remaining following miscarriage or termination of pregnancy before 24 complete weeks of pregnancy, however, Aneurin Bevan University Health Board will provide care and support to parents in whatever decision they make. The following guiding principles will form the basis of the policy:

General

- Parents are given a choice over what happens to the pregnancy tissue. The choices are explained sensitively and the relevant information is given to the parents as early as is possible.
- The Health Board and its staff will be sensitive to parents' wishes including those who do not want any involvement.
- Some parents may need longer to decide what they want to happen to the pregnancy tissue, but this has to be in accordance with the restraints of the Pathology Department
- Sensitive written information will be available to parents. The written policy on handling the loss of a baby before 24 weeks will be available to all staff

- Staff will provide support and advice to parents and ensure that they have time to grieve. This includes pastoral advice from the chaplaincy department and contacts for other religious groups if they so wish.

Pathological examination

- All pregnancy tissue where there are no grossly identifiable fetal parts will be sampled and processed as a histological specimen for histopathological diagnosis. Blocks and slides which have been prepared from the sample of this tissue will be retained in the histopathology departments as recommended by the Royal College of Pathologists guidelines. Surplus tissue will be disposed of lawfully in hospital incineration, after a period of one month following diagnosis.
- All pregnancy tissue where a grossly identifiable fetus or fetal parts are present in the specimen sent for histological examination, will only be returned to the clinical area from which it was sent, if there is no consent from the mother or where parents have opted for private cremation the tissue will be returned to the ward. The doctor must ensure that there is the printed sticky label, confirming the parents wish to have any fetal remains disposed of in the hospital, attached to the histology form and this must be signed and dated by the doctor. Fetal examinations are not made at Nevill Hall or Royal Gwent Hospitals. Parent's wishes with regards to the disposal should be sought at the time of deciding on the management of miscarriage and consent obtained and documented in the ICP.
- Pathological examination at ABUHB is only for the purposes of confirming pregnancy tissue and examining for any molar changes
- Any further examination of the fetus is performed at UHW. Post Mortem Consent (Appendix 10) from the parent/s is required together with an application form by the medical practitioner (Appendix 6). Appendix 6 and 10 will need to be sent along with the fetus.
- See appendix 7 for the Procedure for transferring fetal material to the fetal pathology unit University Hospital of Wales and see appendix 8 Cardiff and Vale University Board fetal pathology unit tissue transfer chain of custody.

Choice for disposal of pregnancy tissue

Although it is not a requirement by law, ABuHB will discuss parents choice over what happens to the pregnancy tissue. The Health Board and its staff will be sensitive to all parents' wishes including those who do not want any involvement.

- **Hospital disposal**

ABuHB will deal with pregnancy loss/fetal tissue under and including 12 weeks gestation. Consent to dispose of the tissue must be obtained and documented in the ICP along with the parents signature. Disposal of fetal tissue in hospital will mean there will not be any ashes for the parent to take home.

- **Private funeral**

Some families may wish to make private funeral arrangements. Staff can provide families with a list of funeral directors. We would suggest that the family go to a funeral director who may be known to them or local to them. The funeral director appreciates how hard it must be for families and will support them in their decision making and choices and any financial concerns they may have. Most often, the charge is much reduced or can be free in these circumstances.

- **Cremation**

ABuHB do not provide cremation for under 12 weeks gestation. Where the pregnancy is over 12 weeks gestation and the parents prefer no involvement or if there are financial constraints the health board will dispose of the remains and this will be undertaken via the mortuary by cremation (completed application forms essential) – appendix 3 .

- **Burial**

ABuHB do not provide burials for fetal tissue, still births or preterm babies. However, where the pregnancy is over 12 weeks gestation and the parents prefer no involvement or if there are financial constraints the health board will dispose of the remains and this will be undertaken via the mortuary by cremation (completed application forms essential) – appendix 5.

- **Home burial**

Some families may wish to have a burial in their own garden. This is legal - however, there are strict regulations in place for burial of any form of human tissue in a domestic environment. The health board can provide information and the contact details for their local council.

Operational Policy

- All discussions with parents regarding the arrangements they wish to make must be fully documented in the Integrated Care Pathway which is placed in the medical notes including the receipt of written information. Consent for agreement to evacuation of uterus following miscarriage of pregnancy should also be placed in the medical notes
- All fetal remains under 12 weeks which are for hospital disposal should have parents consent obtained and documented in the ICP.
The parent must sign in the ICP that they consent to ABuHB disposing of fetal tissue under 12 weeks as previously highlighted. This will also be documented, signed and dated by the doctor on the histology form.

All fetal remains sent to the mortuary for private funeral or ABuHB arrangement **must have the following documentation**, which includes signed consent from the parent **"Application for the Cremation of Fetal Remains" (Appendix 3)** or **"Application for the Burial of Fetal Remains" (Appendix 5)**. Also a member of the medical staff must complete and sign the **"Certificate of Medical Practitioner in respect of Fetal Remains" (Appendix 4)**.

- Ideally, parents should make a decision regarding the disposal before leaving the hospital and will **have** to sign the required documentation for their fetus whether this is to be disposed of by ABuHB- under 12 weeks gestation admitted to pathology, Private funeral or ABuHB cremation admitted to the mortuary. However, where the parents leave the hospital without making a final decision, it should be made clear that after 2 weeks the Health Board will contact them requesting conclusion to the arrangements they wish to make. If no instructions are received, the Health Board shall dispose of the remains by cremation after a total of 4 weeks.

Fetal tissue for hospital disposal will not be processed without consent and therefore would have to be cremated using the ABuHB contracted funeral directors.

- Where the family request home burial the arrangements in each County Borough vary slightly and staff can provide the relevant information sheet to advise parents of council requirements and telephone numbers.

- **Health Board Funerals arrangements**

As per the Health Board Policy and Procedure for Health Board Arranged Funeral **GHT/0102** the Health Board will pay for the funeral (cremations) arranged by the contracted funeral directors and provide a Hospital Chaplain to be present if the parents wish.

Cremation of fetuses between 18 and 24 weeks gestation – The contracted funeral director will provide a chipboard casket covered in white plastic/dommette suitably finished to good standard, waterproofed with gown and frill.

For parents who experience miscarriage before 18 weeks gestation, the 'coffin' may not be as specified above

The contracted funeral director whom ABuHB deal with do not feel able to offer any of the following services and parents need to be aware that the following cannot be provided, so that there are no misunderstandings:

Notice in local papers

Flowers

Transport for parents or family members

Use of the funeral home prior to the funeral

Parents or their representative who wish to place notice in local papers may make their own arrangements.

Parents or their representative planning to attend the funerals will need to arrange their own transport arrangements and bring flowers if they wish.

There are normally some ashes which if desired, can be collected after two days from the Crematorium. If the parents are married either can collect, if not, only the mother can. In either case,

photographic ID such as a driving licence or passport is required for collection.

If the parent does not have photographic ID they should contact the crematorium for advice before going to collect the ashes.

Please note that, Crematoria practice now is to make the ashes available 48 hours after the funeral. Where details of the next of kin is known, that person is contacted by letter to inform them that the ashes are available and will be held for a further four weeks. If after this time, no contact has been made and the ashes have not been collected they are buried in the garden of remembrance in the crematorium grounds.

Role of the Chaplaincy Department

The Chaplaincy service offers support and advice, pastoral counselling and other practical help which may be of value to parents during what is clearly a distressing time. When requested chaplains help families to plan the funeral and can officiate at the service.

Chaplains are available to visit the mother/father on the ward when a Fetus/baby is delivered and will if requested offer prayers, a blessing, a naming service or Baptism / Christening.

The chaplaincy department arranges two annual Memorial Services. Parents can attend one of these services and if they wish, participate in an act of remembrance. In Nevill Hall an annual baby memorial service is held on Easter Saturday and the Royal Gwent arranges a service usually held on the first Sunday in June. (Further information is available from the chaplaincy office, level 3, Royal Gwent Hospital or the Chaplaincy office in Nevill Hall

Books of Remembrance

In the Royal Gwent Hospital books of remembrance are held on gynaecology, maternity and neonatal wards and parents can arrange with staff for an entry into a book as a commemoration of their baby.

In Nevill Hall a remembrance book covering gynaecology, maternity and special care wards will be housed in a memorial book case in the chapel situated off the main concourse.

Responsibilities

1 Management Responsibilities

- The Health Board management is responsible for negotiating and arranging a contract with a local funeral director. This contract is structured to reflect systems for quality control and assurance.
- There will be liaison and on-going dialogue with the funeral directors to enable sensitive changes to be made to the terms and content of the contract based on client feedback and observations.
- Where the parents have decided to arrange the funeral the health board will also ensure the correct paper work is available for the funeral director to collect with the fetus from the mortuary.
- Where the health board is organising the funeral the contracted funeral director will receive the relevant forms by fax. The contracted funeral director then notifies the health board of the date and time of the funeral. An order must be placed with the contract funeral firm for every ABuHB arranged cremation. Ward staff must ensure that an oracle order is raised and they are in receipt of the code
- Appropriate multidisciplinary training will be provided to staff by the Health Board to enable them to manage the process in a knowledgeable and sensitive manner.
- Managers ensure that staff has time to devote to parents who require additional support as a result of the loss of a baby regardless of gestational age.
- Post mortem examinations of non-viable fetal remains are carried out at the Fetal Malformation Unit (FMU), Institute of Medical Genetics, University Hospital of Wales (UHW). The remains are transported directly to the FMU from the ward concerned. The medical practitioner form (see appendix 4) should accompany the fetal remains at all stages of the investigation, storage and transportation until disposal. The remains are transported back to the mortuary in the Royal Gwent Hospital and Nevill Hall Hospital, to await release to the funeral firm concerned. The mortuary staff will be responsible for notifying the respective department that the fetus has been returned to the hospital.

- Information leaflets and advice are available.

2 Staff Responsibilities

- Staff must inform obstetrics Medical records and radiology of miscarriage where appropriate to ensure further appointment is not sent
- Staff will at all times respect the rights of the parents to have time to grieve and say goodbye to their baby in a supportive environment during the initial period of bereavement.
- Staff will accommodate the wishes of the parents and other family members into their management of the initial bereavement period.
- Where parents decide to make private arrangements, help will be offered to ensure a smooth transition to the private agency.
- Staff will know the names of support agencies within the community to enable further support for parents if they desire. (information leaflet)
- Staff will know how to contact representatives of other non-Christian organisations or religious faiths for members of those communities; information is available at ward level. The Chaplaincy department is also available to help with this.
- Staff must always record the decision of the parents in the Integrated care pathway be placed in the mother's medical records. Copies of signed documentation will be retained in the parent notes.
- Staff will ensure that the Consent and Disposal and Medical Certificates are completed for fetuses over 12 weeks not being transferred to UHW for a post mortem. Copies of signed documentation will be retained in the mother's notes.

3 The Parent's Responsibility

- Parents are required to decide on their choice of disposal as outlined in the policy above. It is not legally required before 24 weeks gestation unless there are signs of life.

- Parents who wish to make private funeral arrangements of a fetus/baby which has been miscarried or who have undergone a termination for abnormality or serious disease between 12 and 24 weeks may be required to pay the costs in full. However Some Funeral Homes may offer a free or reduced price service.
- Parents can opt for a health board cremation, where there are financial constraints or where they do not wish to be involved with the funeral, through the Health Board's contract service free of charge to the parents.
- Parents may decide if they wish to receive the services of the hospital chaplaincy or may choose to make their own arrangements.
- Parents and family may attend any funeral service that is provided by the Health Board for their baby.

4 Review of Policy

Health Board policies are reviewed every three years.

Bibliography

Confidential Enquiry into Stillbirths and Deaths in Infancy, The Fetal and Infant Post-mortem: Brief Notes for the Professional, Maternal and Child Health Research Consortium, London

Department of Health (1998) *Guide to the Post-mortem Examination: Brief Notes for Parents and Families Who Have Lost a Baby in Pregnancy and Infancy*, Department of Health, London

Royal College of Nursing (2007) *Sensitive Disposal of all fetal remains: Guidance for nurses and midwives*, RCN, London

The Paediatric Pathology Service for Wales, *Information for Parents: Post-mortem examination of babies and children*, Cardiff and Vale NHS Health Board, NHS Cymru Wales.

NHS Management Executive, Health Service Guidelines, HSG (91) 19, *Disposal of fetal tissue*

Welsh Office, WHC (91) 96, *Disposal of Fetal Tissue*

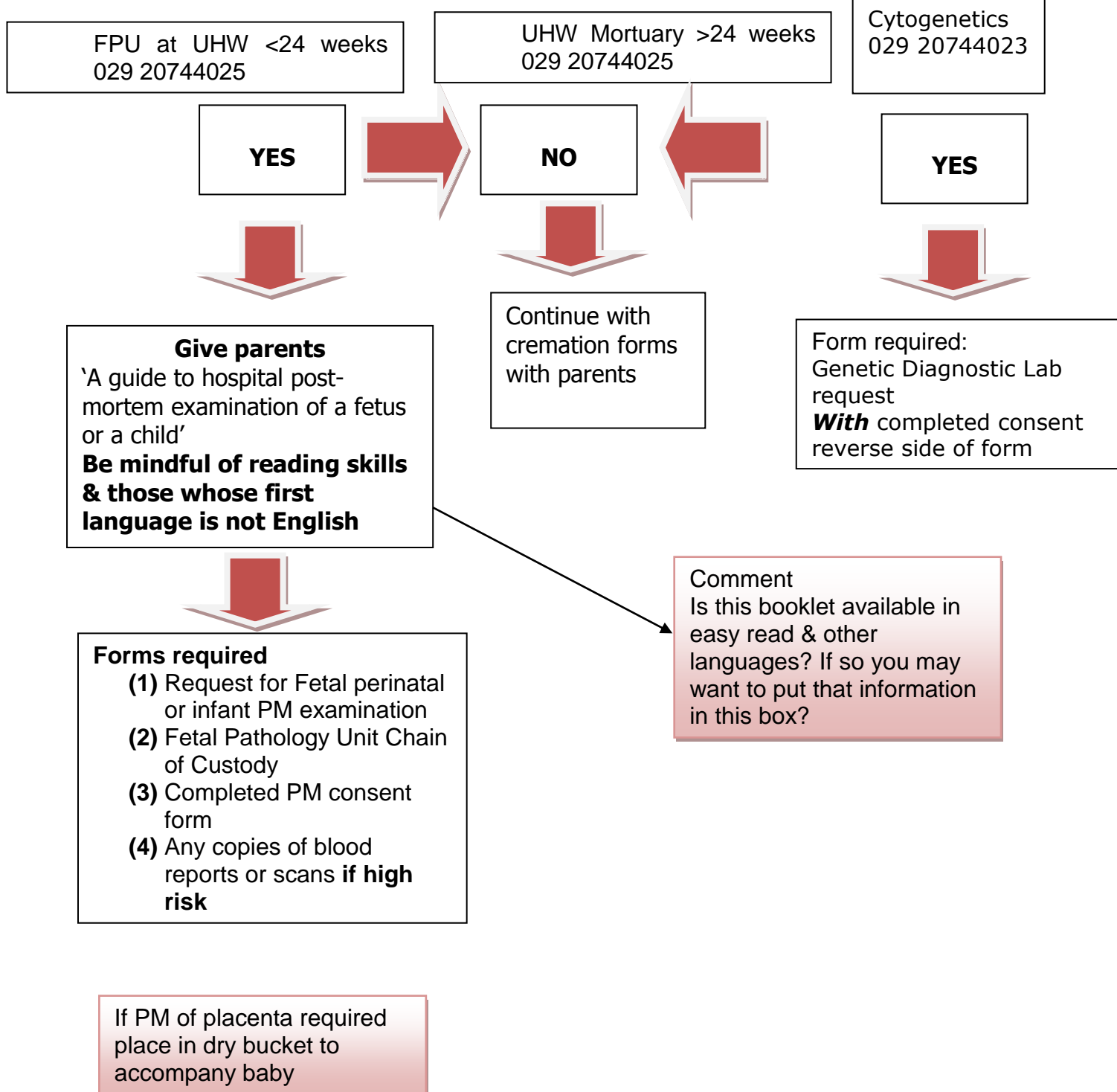
The Royal College of Pathologists (2002), *Interim guidelines for the disposal of tissue, block and slides from biopsies and surgical resections*.

Royal College of Obstetrics and Gynaecologists (October 2006)
Green Top Guidelines. 25 The Management of Early Pregnancy Loss

Human Tissue Authority September 2009. *Codes of Practice on Consent, Post-mortem Examination, Removal, storage and disposal of human organs and tissue*.

Appendices

Appendix 1 Post-mortem or Tissue sampling for Cytogenetics Forms for Post-mortem



Appendix 2 CREMATION FORMS

Cremation Form
for Foetal
Remains
< 24 weeks
(Less than)
gestation)

Cremation
Formfor a
Stillborn Child
>24 weeks
(more than)
gestation
- born showing
no signs of life)

Cremation Form
4
**Only to be
used if any
signs of life**

For parents requesting private burial

Application for the Burial of Fetal
Remains for over 24 weeks only.
Unless exceptional
circumstances or cultural
/religious reasons

Appendix 3 **SAMPLE** Application for cremation of fetal remains

	Cremation No. <input style="width: 100%;" type="text"/>
APPLICATION FOR THE CREMATION OF FOETAL REMAINS	
Gwent Crematorium, Treherbert Road, Croesyceiliog, Cwmbran, Torfaen. NP44 2BZ Tel: 01633 482784	
Application for the cremation of foetal remains to be made to the Superintendent and Registrar, Gwent Crematorium. Such application to be accompanied by the Registered Medical Practitioner's Certificate in respect of foetal remains.	
PART 1 - YOUR DETAILS (THE APPLICANT)	
Your full name :	<input style="width: 70%;" type="text"/>
Address: Including postcode	<input style="width: 70%;" type="text"/>
Telephone number	<input style="width: 30%;" type="text"/> <input style="width: 30%;" type="text"/> <input style="width: 30%;" type="text"/> <input style="width: 30%;" type="text"/> <input style="width: 30%;" type="text"/> <input style="width: 30%;" type="text"/>
PART 2 - THE APPLICATION	
I, * being the parent / not being the parent, (delete as appropriate) make application for the cremation of the remains of : (In the case of a foetus who has not been given a name, in place of a name insert a description sufficient to identify the baby.)	
Name of baby <input style="width: 80%;" type="text"/>	
Mother's Name (if not the applicant) <input style="width: 80%;" type="text"/>	
delivered on: (date)	<input style="width: 15%;" type="text"/> <input style="width: 15%;" type="text"/> / <input style="width: 15%;" type="text"/> <input style="width: 15%;" type="text"/> / <input style="width: 15%;" type="text"/> <input style="width: 15%;" type="text"/>
	Male <input type="checkbox"/> Female <input type="checkbox"/>
At (address or name of hospital) <input style="width: 80%;" type="text"/>	
PART 3 - DISPOSAL OF THE CREMATED REMAINS	
I acknowledge that it may not be possible to recover any remains following the cremation and if this application is made on behalf of the parent(s) that this possibility has been made known to them. If remains can be recovered, I wish for them to be disposed of in the following manner:	
Buried in the Garden of Remembrance at the crematorium	<input type="checkbox"/>
Made available for collection by the funeral director An extensive range of urns and keepsakes can be viewed on our website www.gwentcrematorium.org.uk	<input type="checkbox"/>
PART 4 - THE DECLARATION	
I apply for the foetal remains to be cremated and I certify that I am at least 16 years of age. I believe that the facts given in this application are true. I am aware that it is an offence to willfully make a false statement with a view to obtaining the cremation of any human remains.	
Print your full name	<input style="width: 80%;" type="text"/>
Signed	<input style="width: 80%;" type="text"/>
Dated	<input style="width: 30%;" type="text"/> <input style="width: 30%;" type="text"/> / <input style="width: 30%;" type="text"/> <input style="width: 30%;" type="text"/>
The Medical Practitioner's Certificate in respect of foetal remains is attached herewith.	
Please turn over	

THIS SECTION TO BE COMPLETED BY THE APPLICANT OR FUNERAL DIRECTOR
Please note this is important information and all questions should be answered

Please state the day, date and time of the service:	
Day	
Date	
Time	
Religious Denomination	
Name of officiant	
Service type	FULL <input type="checkbox"/> COMMITTAL <input type="checkbox"/>
Family Attending	YES <input type="checkbox"/> NO <input type="checkbox"/>
Organist required	YES <input type="checkbox"/> NO <input type="checkbox"/>
Curtains to remain open	YES <input type="checkbox"/> NO <input type="checkbox"/>
Webcast Service	YES <input type="checkbox"/> NO <input type="checkbox"/>
Record Service	AUDIO <input type="checkbox"/> VIDEO <input type="checkbox"/> NO <input type="checkbox"/>
Please state what music is required. A minimum of 24 hours notice is required for music to be played on the Wesley Music System.	
Entry music	
Hymn/Song 1	
Hymn/Song 2	
Exit music	
Name and address of Funeral Director	Telephone No: _____
Signature of Applicant / Funeral Director	

Cremation will be carried out within 24 hours of the funeral service in compliance with the Code of Cremation Practice and the Guiding Principles of the Charter for the Bereaved.

Where the Funeral Director signs this form on behalf of the Applicant, he/she must accept full responsibility for any instructions given.

The details in this form will be used for the purpose of providing the applicant with information about the crematorium's memorials and other facilities.

If the applicant does not wish to receive such information please tick here ☐

Appendix 4 **SAMPLE** Certificate of medical practitioner in respect of fetal remains

CERTIFICATE OF MEDICAL PRACTITIONER IN RESPECT OF FOETAL REMAINS			
Gwent Crematorium, Treherbert Road, Croesyceiliog, Cwmbran, Torfaen. NP44 2BZ Telephone and Fax: 01633 482784			
Please complete this form in full, if a part does not apply enter N/A			
Part 1: THE FOETAL REMAINS			
I hereby certify that I have examined the foetal remains of:			
Mother's Name			
of Address			
	Postcode: <input type="text"/>		
Delivered on	<input type="text"/> / <input type="text"/> / <input type="text"/>	At	<input type="text"/> am/pm
Of	<input type="text"/> weeks	gestation and that at no time was there any sign of life.	
Part 2: CERTIFICATE OF FOETAL REMAINS			
I have no reason to suspect that the duration of the pregnancy was shortened by violence, poison or any other unlawful act and I know of no reason why any further examination or enquiry should be made.			
Print Name			
Address			
Telephone No (office hours)	Postcode: <input type="text"/>		
	<input type="text"/>		
Medical Practitioner's signature			
Registered Qualifications		Dated	

Appendix 5

SAMPLE APPLICATION FOR THE BURIAL OF FETAL REMAINS

Parent/Person acting with the parent's permission

I _____

of _____

** being the parent/* not being the parent (* delete as applicable) make application for the burial of the fetal remains of*

Print Name _____

Signature of applicant

Date _____

Clinician

I hereby certify that I have no reason to suspect that the duration of the pregnancy was shortened by any unlawful act, and that I know of no reason why any further enquiry or examination should be made.

Fetus of _____

Delivered on _____

At _____

Name of Clinician – Print

Signature of clinician

GMC Number

Bleep Number

Date _____

Appendix 6 **SAMPLE** Request for fetal, perinatal or infant post mortem

EF-MOR-PMRequest

Revision 1.0

4.12.13

Paediatric Pathology Service for Wales

Department of Pathology, University Hospital of Wales, Heath Park, Cardiff CF14 4XW

Professor Gordon Vujanic, Professor of Paediatric Pathology, 029 2074 4649, vujanic@cf.ac.uk

Dr Ed Lazda, Senior Lecturer in Paediatric Pathology, 029 20 742703, lazdaej@cf.ac.uk

Paediatric Pathology Secretary

Tel 029 2074 2706

Fax 029 2074 8490

Fetal Pathology Unit

Tel 029 20 744025

Fax 029 20 744074

Request for fetal, perinatal or infant post mortem examination

Please complete all relevant sections of this form to ensure appropriate examination and avoid delay

Form completed by

Name.....

Signature.....

Hospital / tel no. / bleep no.....

Contact for discussion or further information

Name.....

Signature.....

Hospital / tel no. / bleep no.....

Mother details

Addressograph

Family name.....

Address.....

Postcode.....

Hospital No. Date of Birth

Date of delivery.....

Consultant; referring hospital & ward.....

Fetus / infant details

Surname.....

First name.....

Date/time of birth.....

Date/time of death.....

Hospital number.....

Consultant.....

Infection risk

This is required information. See "Safe working and the prevention of infection in the mortuary and post-mortem room", HSE, 2003.

Is there any danger of infection (HIV, viral hepatitis, TB, etc) from the baby or placenta? **Y / N**

Specify:.....

Any special points of interest?

Mother's medical history

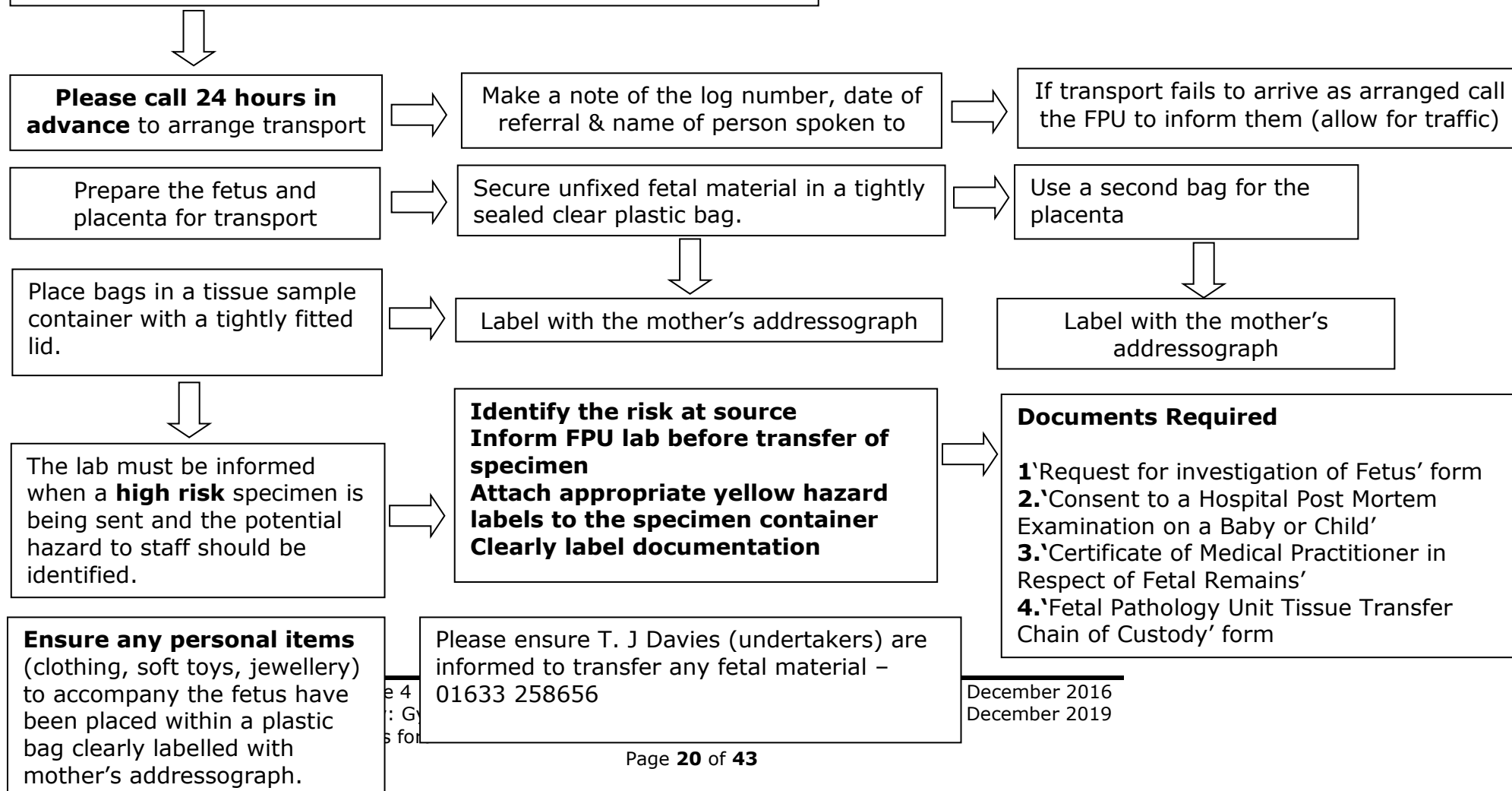
Blood group.....

Past obstetric history

Date; gestation; weight; details of pregnancy, labour and delivery

Appendix 7 Procedure for transporting Fetal material to the Fetal Pathology Unit, University Hospital of Wales

The opening hours for the Fetal Pathology Unit are **Monday to Friday 9.00am – 16.30pm (excluding bank holidays).**
029 20 744025



December 2016
December 2019

Appendix 8 **SAMPLE** Chain of custody form

Cardiff and Vale UHB	Revision: 5	Filename: PD-HIS-FPUCustody
Cellular Pathology Services	Date of issue: 11/10/2011	Page 1 of 1

**Cardiff and Vale University Health Board
 Fetal Pathology Unit Tissue Transfer Chain of Custody Form**

PLEASE FAX THIS FORM TO 029 2074 4074 IN ADVANCE OF TRANSFER TO THE FPU

this will give prior notice of intention to transfer fetal material

Box 1 Name of Mother (Addressograph)

Date of Birth.....

Box 2

Date of transfer.....

Specimen type.....

Name of referring Hospital.....

Fax Number.....

PART A.

Signature of consigner (referring Health board).....

Print name.....

Date..... Time.....

PART B.

Signature of transport driver / Porter.....

Print name.....

Date..... Time.....

PART C.

Signature of consignee (FPU, UHW).....

Print name.....

Date..... Time.....

The completed form will be faxed to the number included in Box 2.

CARDIFF AND VALE FETAL PATHOLOGY SERVICE

Appendix 9 **Sample**

Home Burial Information sheet

Monmouthshire Council

Mike Richardson (south) 01291 635709

Huw Owen (north) 01873 735433

Powys Council

Powys is 0845 6027037 and ask for cemetery/ burial services

Blaenau Gwent

01495-311556 and ask for Bereavement Services

Caerphilly council

Lyndon Ross - Senior Environmental Health Officer - 01495 235276.

Torfaen council there is nobody specific to contact but parents can look for advice on the natural death centre website or email

Public.Health@Torfaen.gov.uk

Cardiff council there are no contact details. Parents need no permission but are advised to look at the information on websites such as the natural death centre for restrictions.

Newport council This is the information from environmental health for Newport Council. There isn't a specific name or number to contact, however this is the information they would provide for anyone contacting them and has been incorporated in this leaflet

1. Individuals must be able to satisfy Natural Resources Wales that the burial will not take place within certain distances of specific types of water; i.e. the gravesite should be on land with a deep water table and be sufficient distance from watercourses so as not to pose a pollution threat. For example the site should be located more than at least 10 metres from any 'dry' ditch or field drain, at least 30 metres from any spring or any running or standing water and more than 50m from a well, borehole or spring supplying potable water for human consumption: there should not be any standing water at the bottom when it is first dug; not be dug in sandy soil and be deep enough to prevent foraging animals from disturbing the body.

These matters should be clarified with the Natural Resources of Wales by contacting their Customer Care Centre on 0300 065 3000 (Mon-Fri, 8am-6pm).

2. Electrical, gas, water, sewerage or other services must be avoided.

3. In the event that a number of burials are proposed, it would be prudent to contact the Planning Authority to confirm the position with respect to planning permission.
4. Care should be given when excavating a gravesite and there should be a sufficient depth of soil 1m (three feet) between the settled soil level and the top of the coffin or shroud.
5. It would be wise to advise neighbours of this proposal. However, I would stress that this is not a legal requirement.
6. In the event that the individual moves from this property, the new purchaser may wish to obtain an exhumation licence and this is something that you must give some consideration to. There are legal means (a restrictive covenant) by which you can ensure the grave remains untouched.
7. There is a requirement for the landowner to maintain a register of burials. This can be in the form of a sheet of paper or notebook, preferably with a plan to show the precise location. This should be kept somewhere accessible and a copy kept with the deeds to the property. This will ensure that the grave is not disturbed by building or excavation works at some stage in the future.
8. The person responsible for the burial must obtain a Certificate of Authority for Burial* from the Registrar of Births & Deaths (or in special circumstances from the Coroner) before the burial takes place (This is routinely issued at the time of the registration of the death, and more commonly referred to as 'the green form'.)

I hope that the above points are of assistance to you. However, should you require clarification on any of these, do not hesitate to contact me or alternatively detailed advice can be found in a publication 'The New Natural Death Handbook', ISBN 0712605762 or through their website www.naturaldeath.org.uk

In reference under 24 completed weeks, please read page 9 within the above document, very useful information

Appendix 10



Consent Form for a Post-Mortem Examination of a Fetus, Baby or Child

CONSENT FOR A POST-MORTEM EXAMINATION OF A FETUS, BABY OR CHILD



Name: _____

Address: _____

Addressograph of
mother or baby
or child if available

D.O.B. _____

REFERRING HOSPITAL'S REFERENCE NUMBER: _____

Name of fetus, baby or child: _____

Mothers name: _____

Fathers name: _____

Date of death: _____ Place of death: _____

Consultant/GP responsible for: _____

Religion: _____

This form enables you to consent to a post-mortem examination of the fetus, baby or child identified above. Please read it carefully with the person obtaining consent from you. For each section **INITIAL** the relevant box(s) or **CROSS (X)** if not applicable.

- I confirm that I have had the opportunity to read 'A Guide to the Post-Mortem Examination of a Fetus, Baby or Child'.
- I have had an opportunity to ask questions about the proposed examination.
- Any questions I have asked have been answered to my satisfaction.

Initial

Part 1: Consent to a post-mortem examination

The reason the examination is requested has been explained to you. The extent of the examination is your decision after discussion (complete A, B OR C as appropriate).

- A.** I consent to a full examination.

Initial

- B.** I consent to an examination, limited to the part of the body as stated:

Initial

(I understand this might limit the information obtained).

- C.** I consent to an external examination of the fetus / baby and histological examination of the placenta (I understand this might limit the information obtained).

Initial

Part 2: Consent for use of samples as part of the post-mortem examination

It is usually necessary to examine small samples in more detail to obtain a reliable conclusion. Most tissue samples will be processed into blocks and slides for microscopic examination and may be used for other investigations. If you do not consent this will significantly limit the value of the examination.

I consent to the retention of tissue samples for processing and further examination as part of the examination.

Initial

Part 3: Consent for retention of a whole major organ (s) or larger blocks of tissue as part of the post-mortem examination.

Sometimes it is necessary to examine a specific organ in more detail to reach a reliable conclusion.

I consent to the following organ(s) or large pieces of tissue being retained for the purpose of the examination (tick below as appropriate);

- ☐ Any if the pathologist feels it appropriate
☐ Any except _____
☐ The following _____

Initial

Please indicate your wishes for the disposal of any retained organ(s) (tick below as appropriate);

- ☐ I consent for future use of the organ(s) (specify in part 4).
☐ I wish the organ(s) to be returned to the body (this may delay the funeral).
☐ I wish the hospital to dispose of the organ(s) in accordance with the Human Tissue Authority Code of Practice.
☐ I will make my own arrangements for lawful disposal.

State arrangements if known: _____

Part 4: Storage and future use of tissue samples (particularly blocks and slides made from the tissue).

Tissue removed can be stored for use in the future and these samples may be of value to your family in the future. Doctors and scientists also require tissue samples for quality control, teaching, public health monitoring and to advance patient care through audit and research. Although it is not common for tissues to be used in this way it can be very important to have this tissue available when the need arises.

Your consent is required for the, storage and future use of these samples (initial ALL that apply).

- I consent to tissue being stored and used on behalf of the family if the need arises.

Initial

- I consent to tissue being stored and used for education relating to human health, quality assurance, public health monitoring and clinical audit.

Initial

- I consent to tissue being stored and used for research that has been approved by an appropriate Ethics Committee.

Initial

If you chose not to give consent for future use, all tissue samples will be disposed of: please indicate your wishes for disposal (tick below as appropriate):

- ☐ I wish the hospital to dispose of any retained tissue samples in accordance with the Human Tissue Authority Code of Practice.
☐ I will make my own arrangements for lawful disposal of any retained tissue samples.

State arrangements if known: _____

Part 5: Additional Tests (tick below as appropriate);

- ☐ I consent to x-rays.
☐ I consent to clinical photographs.
☐ I consent to genetic testing including the taking and storing of appropriate samples.

Initial

Part 6: Special requests:

Right to change your mind (see Note 1):

Thank you for consenting to a post-mortem examination. You can change your mind about any of the decisions you have made, although there may be a short time limit for some of these. If you wish to make changes to anything you have consented to, or wish to withdraw your consent, please contact the number as specified below:

Before (time): _____ on (date): _____

Contact: _____ Telephone number: _____

Details of person(s) giving consent:

Name: _____ Signature: _____ Initial

Address: _____

_____ Tel no: _____

Relationship to the deceased: _____ Date: _____

Second parent if they wish to sign: _____

Details of person(s) obtaining consent (see Note 2):

Name: _____ Job title: _____

Contact details: _____

Health Board: _____ Identifier: _____

- Where appropriate, I have discussed the requirements of the post-mortem examination with: _____ *(Pathologist or The Fetal Pathology Unit)*

Statement of the person(s) obtaining consent

- I have made enquiry and believe that the person consenting is the appropriate person and they have parental responsibility (see Note 3).
- I believe that the person consenting has a sufficient understanding of the post-mortem examination procedure for the purposes of giving consent.
- I believe that the person giving consent has sufficient understanding of why material is being removed, stored and used for future use and understands the options available for the tissue including donation for scheduled purposes and subsequent disposal.
- I have discussed any special requests or conditions concerning the post-mortem examination procedure.
- I have examined the answers and have not identified any ambiguities or conflicts in the way the consent giver has completed the form.
- I have offered a copy of this completed form to the person giving consent.

Signed: _____ Date: _____

Note 1: If consent is subsequently withdrawn or amended, each page of each copy of the form (or the relevant section(s)) must be clearly struck through. The person taking the withdrawal must sign and date the form clearly, and note action taken to inform the mortuary (document the date, time and member of mortuary staff informed.)

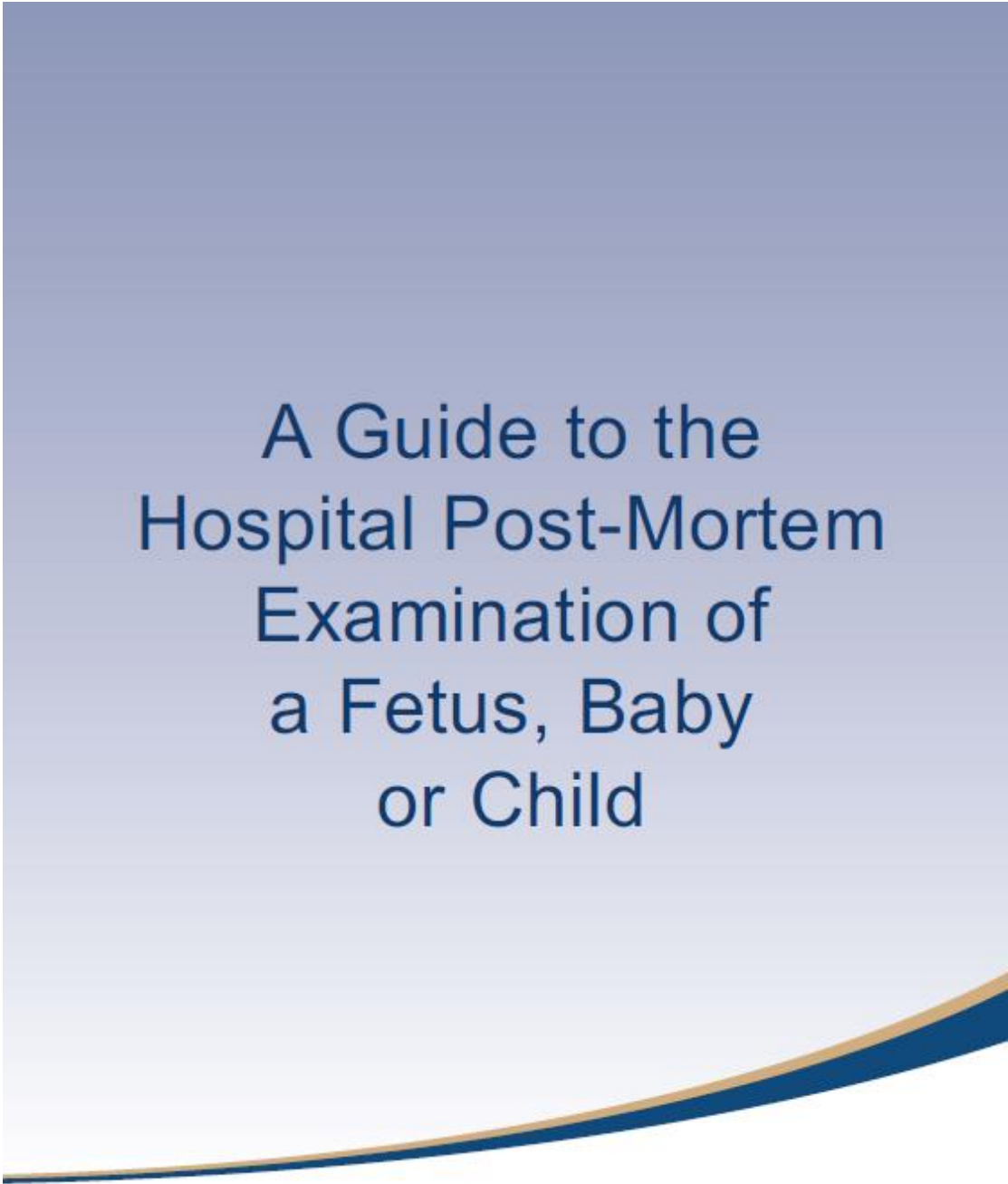
Note 2: Must be legible and include the Health Board responsible and a unique identifier (e.g. professional registration number or NHS email address).

Note 3: The person(s) with parental responsibility will usually, but not invariably, be the child's birth parents. People with parental responsibility for a child include: the child's mother; the child's father if married to the mother at the time of the child's conception, birth or later; a legally appointed guardian; the local authority if the child is on a care order; or a person named in a residence order in respect of a child. Fathers who have never been married to the child's mother will only have parental responsibility if they have acquired it through a court order or parental responsibility agreement (although this may change in the future). Alternatively, any person in a qualifying relationship. **NB** - For advice on specific cases please contact the Human Tissue Authority directly on Tel: 020 7211 3400.

White copy to Pathologist Green copy for medical notes Pink copy for the family

Version 1, May 2010

Appendix 11

The image shows the front cover of a guide. The background is a light blue gradient. In the center, the title 'A Guide to the Hospital Post-Mortem Examination of a Fetus, Baby or Child' is written in a dark blue, sans-serif font. At the bottom of the cover, there is a decorative wavy line in shades of blue and gold. In the bottom right corner, there is a logo for GIG Cymru NHS Wales, which consists of a stylized blue knot-like symbol next to the text 'GIG CYMRU NHS WALES' in blue and gold.

A Guide to the Hospital Post-Mortem Examination of a Fetus, Baby or Child



Introduction

You have been asked to read this booklet because your fetus, baby or child has died. On behalf of our staff, we would like to express our sympathy to you and your family following your loss.

We understand that this is a difficult time for you to consider the issue of a post-mortem examination, but we hope this booklet will help you understand the reasons for undertaking it, what it involves, and why it may be important. Please take time to read the guide and discuss it with your family if you wish, before you complete the consent form. We encourage you to ask us if anything is unclear or if you have any questions.

You may wish to speak to another member of staff, possibly someone you got to know while they were looking after you. The main thing to remember is that you can ask as many questions as you like and if you would rather not hear details that you find upsetting, just say so. Our staff are aware that this is not an easy subject for people to deal with and they will want to help you make the decisions that are right for you and your family.

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What is a post-mortem examination?

A post-mortem is an examination of a body after death; it is also called an autopsy. An examination on your fetus, baby or child would be carried out by a Consultant paediatric pathologist. These are highly specialised doctors and experts in the diagnosis of disease and the identification of the cause of death in children under the age of sixteen.

Why carry out a post-mortem examination?

A post-mortem examination can provide information about the illness or other cause of death. Without a post-mortem, the cause of death can be wrong in up to 30% of cases, although it is worth pointing out that even a post-mortem examination cannot always provide a reason for the death.

Post-mortem examinations help the medical profession by providing information about illness and health that would not be discovered any other way. This examination can help families try to understand why the death has occurred. Sometimes questions arise that can only be answered with information from a post-mortem.

It can also help to:

- identify other conditions that may have been present but not diagnosed.
- assess the effects of treatment and drugs, and identify any complications or side-effects.
- offer information for future pregnancies.
- detect potential health problem that run in families.
- answer questions that as parents you may have in the future.

Donating organs for transplant is handled separately from the post-mortem procedure. Please ask if you want to know more.

Who decides whether a post-mortem examination should take place?

A hospital can ask that a post-mortem examination is carried out, but this can only be done if consent to such an examination is given by the person (s) with parental responsibility or any person in a qualifying relationship.

***Parental Responsibility:** The person(s) with parental responsibility will usually, but not invariably, be the child's birth parents. People with parental responsibility for a child include: the child's mother; the child's father if married to the mother at the time of the child's conception, birth or later; a legally appointed guardian; the local authority if the child is on a care order; or a person named in a residence order in respect of a child. Fathers who have never been married to the child's mother will only have parental responsibility if they have acquired it through a court order or parental responsibility agreement (although this may change in the future). The suitability of any consent given will be established by the person taking consent during the consent process.*

What am I/we being asked to consent to?

This will depend upon the particular circumstances that apply. You may be asked to consent to a full or limited examination. The doctor or other health care professional who discusses the post-mortem with you will explain what the options are.

Usually an examination will involve the opening of the body, and the removal of organs for examination. It may be valuable to retain samples of tissue from various organs and collect body fluids to examine under the microscope. Sometimes it may be advisable to retain an entire organ for a short period of time for a more detailed examination. If this is the case this will be discussed with you and you will have the opportunity to agree or refuse.

You may prefer a limited post-mortem examination where only an agreed part or parts of the body are examined or certain samples removed. Sometimes such examinations can be very useful but this depends on individual circumstances. It may be that a limited examination would not be beneficial or worth doing, in which case we will advise you of this.

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What if I/we don't want a post-mortem examination to be carried out?

Information from a post-mortem may help you have a subsequent successful pregnancy and for this reason your doctors may strongly recommend one as this may be the only opportunity you and they have to get this information.

However if the hospital requests a post-mortem examination you are under no obligation to agree to one; the choice is entirely yours.

When is the post-mortem examination done?

Post-mortems are usually carried out within 2 to 3 working days of death; this is because the earlier the examination is made the more likely it is to provide useful information.

If your pregnancy is less than 24 weeks duration the examination will take place in the Fetal Pathology Unit at the University Hospital of Wales, Cardiff. If more than 24 weeks duration including baby and children it will take place in the mortuary at the University Hospital of Wales, Cardiff. On occasions, post-mortem examinations on children are carried out at local hospitals, the person taking your consent will advise you if this is the case. If you must have a funeral within 24 hours because of your religion, please let us know and we will try to accommodate your wishes.

Who is present during the post-mortem examination?

The pathologist is responsible for the entire examination but is often helped by other staff including trained anatomical pathology technologists (APT's) or other health care staff. Sometimes members of the medical team who have looked after your fetus, baby or child in life will wish to be present, so that they have a complete understanding of what is found and can discuss the significance of the findings with the pathologist.

Occasionally medical students and other health care professionals may attend a post-mortem for educational purposes. If you do not wish for them to be present please say whilst completing the consent form and we will comply with your wishes.

What happens during the post-mortem examination?

- A full examination usually involves removal of all their major organs. They are examined and then returned to their body, although the procedure may differ according to their size.
- In a limited post-mortem examination some of the organs or one part of the body (e.g. chest) may be examined.
- During an external examination a visual examination is carried out and measurements are taken. Photographs and x-rays are also sometimes taken with your consent.

During the process tissue samples may be retained and occasionally, other samples (such as blood) may be required for tests. Sometimes it is beneficial to keep a whole organ so that it may undergo a period of preservation before a more detailed examination is conducted. If this is the case this will be discussed with you.

The pathologist will work to standards set by the Royal College of Pathologists and the Human Tissue Authority (HTA) and will only remove and examine organs or tissues in accordance with your wishes as outlined in your completed consent form.

What happens to tissue samples removed for a more detailed examination?

Small samples of tissue will be taken for further examination in order to make a diagnosis. These samples are processed into paraffin wax blocks called tissue blocks and are contained in plastic cassettes. If removed, their analysis will always be part of the post-mortem examination and findings will be part of the post-mortem report.



A BLOCK (size compared with £1 coin)

Thin tissue sections can then be cut with a sharp knife from these tissue blocks. These sections are very thin, ten times thinner than a hair. They are placed on glass slides and stained with special dyes to allow examination under a microscope.



A SLIDE (size compared with £1 coin)

During the process of making the blocks and slides it is inevitable that very small amounts of tissue will be surplus to requirements, these will be disposed of according to hospital policy.

Does the hospital keep tissue samples removed during the post-mortem examination?

Tissue blocks, glass slides, tissue samples and organs will be kept only if you have given your consent. Tissue blocks and glass slides can be very useful and it is strongly recommended that they are kept at the hospital, but again this is your choice. Having slides as a permanent record means that any diagnosis made can be checked by another pathologist, if required.

They may be of value to a family because ways of examining tissues improve year-on-year and in cases of genetic disorders looking back to the tissue of deceased family members may help to make a diagnosis in living members of the family. Tissue blocks and slides may be used in training doctors and other health care professionals. They are also helpful for quality assurance and audit purposes, for example, they can be used to check on standards in a hospital pathology service.

What if I/we decide that we do not want the tissue blocks and slides retained?

If you decide that their tissue samples should not be kept after the post-mortem examination, we will comply with your wishes.

Will their tissue samples be used for general medical research?

Only if you give your permission. With your consent tissue blocks and glass slides can be used in research which may benefit other people in the future. When a new disease or health problem emerges, examination of tissue may provide clues about how and why the disease emerged – and how to respond. Special committees must approve any research to make sure it is ethical and that sufficient consent has been given. Tissue must not be used for research without your agreement.

■ **Are photographs taken during the post-mortem examination?**

Often the pathologist will take x-rays or other images (including photographs) during the examination to be studied later. These images are usually kept indefinitely as part of the medical record. They may also be used for medical education, audit or research in which case any information which would allow your partner or relative to be identified would be removed. If you object to images being used in this way you must say so when you complete the consent form.

■ **Will genetic tests be undertaken?**

In some instances they will be undertaken if the pathologist decides they are necessary. It involves a small piece of skin or tissues sample (the size of an end of a pencil) being examined. The information obtained might be of help to you, your family and future pregnancies.

■ **What happens after the post-mortem examination is completed?**

If you do not wish any retained tissue to be returned to your fetus, baby or child or if no tissue has been retained at the examination then the Funeral Director may collect them shortly following the examination. If you wish retained organs or tissues to be returned to their body there may be a delay; we will discuss any possible delays with you.

If your fetus / baby is less than 24 weeks gestation and is having their examination at the Fetal Pathology Unit there is usually delay of a few weeks before they are released. If you wish to discuss this, please contact the person whose details are included on page 15.

Can I/we see our fetus, baby or child after the post-mortem examination?

Yes of course you can but every case is different, please discuss this with hospital staff or your funeral director.

How can I/we find out the results of the post-mortem examination?

A copy of the post-mortem report will be sent to the doctor who was in charge of your fetus, baby or child's care at the hospital. This is usually the consultant. Sometimes families request that the report is sent to their GP. The report usually takes six to eight weeks to be finalised, when all the tests are completed, but please be aware that on occasion it can take a little longer.

Why do hospitals need donated tissue samples and organs for medical research, education, audit or quality assurance?

Examining tissue is one of the most important ways in which doctors learn about illness and how to treat it. Tissue blocks and slides are used to train medical students and new doctors, to help experienced doctors continue to learn about new conditions, treatments, or to teach specialist areas of knowledge.

Sharing information between doctors is important in maintaining high standards of care. Doctors training to be pathologists need to watch and learn about post-mortem examinations. Sharing information between doctors and hospitals is also very important for public health surveillance – making sure that infectious diseases (such as hepatitis or measles) do not spread throughout the local or national population.

Medical education, audit and quality assurance are in an integral part of health care. However, we will only use retained tissues whether they be organs, tissue blocks or slides for these purposes if we have your consent to do so.

Research is vital for the progress of medicine. Thanks to it, we can understand and, in many cases, cure diseases that were incurable in the past. The majority of research adds just a little understanding to the building of knowledge – occasionally it is ground-breaking. But all research is important, even if it does not merit a newspaper headline. We ask for your help to continue improving our knowledge and our ability to help other patients.

Can I/we choose to donate their tissue samples or organs just to certain areas of research?

Yes you may. If there is any particular type of research you are interested in or worried about you should discuss this with the person taking consent.

What happens to their tissue samples or organs donated for medical research, education or audit?

They cannot usually be returned to you. After they have been used, they would normally be disposed of by incineration. In some cases they may be used for many years before disposal.

■ Is the consent form binding?

Consent is needed before an examination is carried out and the consent form acts as a written record of your decisions, making it clear to everyone what you have and have not agreed to.

If you change your mind before the examination has taken place, you can modify or withdraw your consent – even after signing the form. If you do change your mind, we ask that you contact the hospital where you completed the consent form. The details regarding who you need to contact will be on your copy of the consent form you completed.

If the post-mortem examination has taken place and you want to change your decision regarding any retained tissues, you may also do this.

■ What if I/we get confused about what we are consenting to?

Our staff should make sure you know enough about the post-mortem examination to decide if you wish to give your consent and they will discuss the alternatives with you. It is important that you come to your own decision and have understood the information you have been given. **If you are not sure, please do not hesitate to say so.** You may want to discuss the options with other family members and then decide. This is perfectly acceptable, as we want you to make the right decision for you and your family.

■ What if I/we require further information?

You can ask as many questions as you like. We work to codes of practice laid down by the Human Tissue Authority. These are available (as is the Human Tissue Act 2004) on the website: www.hta.gov.uk which also contains further information which you may find useful.

The amount of information people require regarding the post-mortem examination does vary. If you would rather not know about certain aspects, please say so. If, on the other hand, you would like more detail or would like to discuss the matter further, one of our pathologists will be very willing to meet with you and answer any questions you may have.

We hope you have found this information helpful at what must be a very difficult time. Should you have any queries or concerns that are not addressed in this booklet, please let us know and we will do our best to help you.

■ Contact Details

1. You have completed your post-mortem consent today
at _____ (hospital).
2. Should you need further information please
contact _____ on
Tel: _____