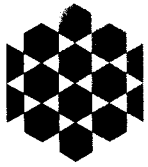

Department of
Health, Social Services and Public Safety

An Roinn
Sláinte, Seirbhísí Sóisialta agus Sábháilteachta Poiblí

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CAREPLAN FOR WOMEN WHO EXPERIENCE A MISCARRIAGE, STILLBIRTH OR NEONATAL DEATH

CAREPLAN FOR WOMEN WHO EXPERIENCE A MISCARRIAGE, STILLBIRTH OR NEONATAL DEATH

Introduction

This careplan has been developed to facilitate and promote quality care for all women who experience a miscarriage, stillbirth or neonatal death. It summarises principles of best practice, based on clinical and professional guidance, consistent with current legislation, and compatible with guidance on informed consent. The aim is to continually improve quality, provide effective care tailored to individual needs, and learn from experience.

Each patient should be provided with the highest possible standard of maternity care and professionals with appropriate skills should be involved at the earliest opportunity. All professionals involved in the care of patients who have suffered the loss of a baby should ensure that the care provided is sensitive, competent and caring.

This careplan is divided into four main sections:

Section I Principles of good practice.

Section II Pregnancy loss before 24 weeks gestation.

Section III Pregnancy loss at 24 weeks gestation or later.

Section IV Loss of a neonate.

There are separate sections for pregnancy loss pre and post 24 weeks. This distinction has been made to reflect a consistency with the legal definition of a stillbirth.

Sections II, III and IV each contain core information in addition to more detailed information relevant to the specific section. This careplan should be used as a framework for the delivery of care. It will however require adaptation to suit specific local services and circumstances. It provides guidance on the minimum standards of care for your Trust and the basis for the development of local care pathways.

Section I - Principles of good practice.

Trusts should supplement this section in accordance with local needs and circumstances.

Aims of this careplan

- To provide health professionals with principles of good practice.
- To promote a sensitive patient-focused approach in the care of patients and their families.
- To facilitate Trusts in producing locally appropriate information and guidance to supplement this careplan.

Definitions

- A live birth is one in which there is any sign of life regardless of gestational age.
- The World Health Organisation (WHO) definition of a live birth states:

"Complete expulsion or extraction from its mother of a product of conception irrespective of the duration of pregnancy which, after separation, breathes or shows any evidence of life, such as beating of heart, pulsation of cord or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta attached".

- A stillbirth is defined as:

"The complete expulsion from its mother, after the 24th week of pregnancy of a child which did not at any time after being completely expelled or extracted breathe or show any other evidence of life". (The Stillbirth Definition (NI)Order, 1992).

Patient Centred Care

- Each patient will have unique needs, which must be recognised and addressed. Decisions must, where possible, be compatible with a patient's wishes, choices and requests.
- Although decisions must be taken by the patient, the participation of her partner and family may be important in decision-making. Where the term 'patient' appears throughout this document it may need to be interpreted as 'the woman and her partner/family'.

Professional Roles

- Professional staff involved must fulfill their statutory obligations to notify the birth and to inform CEMACH (Confidential Enquiry into Maternal and Child Health) or the coroner where applicable.
- A network of lead bereavement training officers will be established to ensure best practice is in place.
- There should be regular audit of practice.
- There should be clear written guidelines for reporting critical incidents.

Patient's Choices

- Staff should be aware that the emotional distress patients experience may present in a variety of ways and staff should be prepared to respond to individual needs.
- All available choices should be clearly and fully explained and patients given time to consider choices and to ask questions. Some of the choices and decisions for patients may include whether to hold, dress or photograph their baby and what burial or cremation arrangements are preferred.
- Staff should formulate a plan and record choices and requests. Every effort should be made to help the patient understand what is happening. A checklist of discussion items should be developed.
- Language should be carefully chosen. Avoid using the terms "non-viable fetus" and "disposal of body", when speaking to patients.
- The individuality of the grieving process must be recognised and acknowledged. The basic principles must be observed including: sensitivity, understanding, compassion, honesty, choice, support, time, privacy, spiritual support and respect.
- The procedures, options and choices available should be discussed with a patient in a quiet and private environment, and documented clearly.
- Staff must respect patients' feelings and choices and recognise their rights to grieve in their own way.
- If there is dissatisfaction or unhappiness with services, patients should be advised of the services of the Patient's Advocate or local complaints process.

Clinical Management

- Normal good practice during and after the delivery should be consistent with available clinical and professional guidance.
- Efforts should be made to provide continuity of care by a senior member of staff experienced in caring for the bereaved.
- Patients should be cared for in a quiet, private environment.
- Appropriate follow-up care should be undertaken.

Counselling Services

- All professionals should be informed of the psychological effect of a pregnancy loss. Support and follow-up is essential. The patient may require referral for formal counselling.

Post Mortem Examination

- The importance of a post mortem should be explained to the patient and offered when considered to be appropriate.

- The nurse/midwife/doctor caring for the patient should discuss and clarify the patient's wishes concerning post mortem and funeral arrangements. In certain clinical situations the patient may need more time, and hospitals may have to accommodate this need.
- When the death needs to be reported to the coroner the patient must be provided with a full explanation supported by written information.

Hospital burial/cremation or own funeral arrangements

- Staff should inform patients of choices regarding funeral or cremation arrangements.

Interpreter and special needs services

- Interpreter services should be available as appropriate.

Dealing with patients of different faiths

- Be aware of and respect the wishes and beliefs of all religions in relation to the care of dead bodies.
- Staff should speak to a patient about particular wishes regarding their religious beliefs.
- Be aware that in some religions, burials must take place within 24 hours of a death.

Care for the professionals

- The focus of care in pregnancy loss is directed initially at the patient and her family. The subsequent requirement may then be to support professional carers.
- Regular debriefing sessions should be offered to all staff who attend and care for bereaved patients. This should be a time for staff to reflect, debrief and identify any concerns or needs, both for the patient and for themselves and identify any areas for improvement.
- Training in loss and bereavement should be provided for all staff who care for patients after miscarriage, stillbirth, or loss of a neonate. As far as possible this should be incorporated into staff induction, and regularly reviewed.

Using this booklet as reference/checklist

A complete copy of this booklet should be held for reference by the following:

- All Maternity Wards.
- Special Care Baby Unit/Neonatal Intensive Care.
- Gynae Wards.
- Community Midwifery Teams.
- Paediatric Units.
- Day Procedure Units/Theatres.
- Accident & Emergency Departments.
- Mortuary and Pathology Departments.
- Chaplains.
- Social Services.

Review of careplan

- This booklet should be subject to review every three years, and revised as required. All changes should be agreed and communicated to each area.

Section II - Pregnancy loss before 24 weeks gestation.

Care and arrangements for patients who deliver a baby of less than 24 weeks gestation with no signs of life, and for the management of miscarriage.

Trusts should supplement this section in accordance with local needs and circumstances.

Introduction

- This section provides good practice guidance for all health care professionals involved in the care of a patient who delivers a baby before the 24th week of pregnancy when the baby, following delivery, does not show any sign of life; or for those experiencing early miscarriage.
- In early miscarriage there may not be an identifiable fetus and traditionally the expelled tissue has been referred to as 'products of conception'. However, irrespective of gestational age, and whether there is an identifiable fetus or not, sensitivity to the needs of patients experiencing a miscarriage is essential.

Status of the fetus

- The Polkinghorne Report, Review of the Guidance on the Research Use of Fetuses and Fetal Material, (1989) states:

  "Central to our understanding is the acceptance of the special status for the living human fetus at every stage of its development which we wish to characterise as a profound respect based upon its potential for development into a fully formed human being... That respect carries over in a modified fashion to the dead fetus in a way analogous to the respect we afford to a human cadaver on the basis of its having been a human being".

  The management of individual patients needs to take account of the period of gestation and the clinical management may be closer to that outlined in section 3.

Patient Centred Care

- Each patient will have unique needs, which must be recognised and addressed. Respect and understanding for the individual nature of experience is fundamental to care. Decisions must, where possible, be compatible with a patient's wishes, choices and requests.
- Although decisions must be taken by the patient, the participation of her partner and family may be important in decision-making.
  Where the term 'patient' appears throughout this document it may need to be interpreted as 'the woman and her partner/family'.
- The patient is most likely to appreciate care when it is individualised to her needs, is agreed in consultation with staff, and recognises the emotional aspects of pregnancy loss.

Guidance for the management of miscarriage

- Clinical management of miscarriage should be consistent with professional guidance, for example guidance issued by the Royal College of Obstetricians and Gynaecologists.
- There should be ready access to services for any patient presenting with a threatened miscarriage. Ideally this includes an appropriately staffed Early Pregnancy Assessment Unit.
- The diagnosis of a miscarriage should be made by a clinician with appropriate experience in obstetric care.
- The options for care should be discussed with the patient in a quiet and private environment. Senior staff should be involved in counselling and adequate time allowed for decision-making.
- If possible, admission should be to an appropriately sited single room.
- Patients with pregnancies of less than 20 weeks gestation are usually managed in a gynaecological ward. If over 20 weeks gestation, a maternity unit is more appropriate. However circumstances may vary according to clinical factors and the physical layout of the Trust.
- If, prior to treatment, a patient wishes to return home to make family arrangements this should be facilitated providing her health is not at risk.

Clinical Follow-Up

- It may be appropriate to investigate the patient for an underlying cause, especially if there is a history of more than one miscarriage. Specific investigations will depend upon individual clinical circumstances.
- The wishes of the patient regarding follow-up should be sought and documented and the necessary arrangements made. This may include a visit by the community midwife/nurse and, if appropriate, a review at the gynaecological clinic.
- Referral to the Regional Genetics Centre should be discussed with the patient if the miscarriage is thought to have a genetic cause.

Post Mortem examination and disposal

- Valid consent should be obtained in keeping with the guidance contained in *Post Mortem Examinations: Good Practice in Consent and the Care of the Bereaved.*

Histopathological Examination and Disposal of Early Miscarriage

- For miscarriages of less than 12 weeks size/crown-rump length less than 6cm, information should be provided and consent obtained as detailed in the *Consent Form for Histopathological Examination and Disposal of Early Miscarriages.*

Post mortem examination following Miscarriage

- For miscarriages of 12 weeks size and above (Crown Rump Length 6cm+) information should be provided and consent obtained as detailed in the *Consent Form for a Hospital Post Mortem Examination of a Baby.*
- Medical staff should be involved in providing information, obtaining consent and counselling patients as appropriate. The booklet *Information for Parents: Hospital Post Mortem Examination of a Baby* should be provided to the patient.

Burial/Cremation

- Consent for burial/cremation should be obtained as detailed in: *Consent Form for Histopathological Examination and Disposal of Early Miscarriages* or *Consent Form for a Hospital Post Mortem Examination of a Baby.*
- Patients may request the hospital to make arrangements for the burial/cremation.
- Following written consent for the hospital to arrange burial/cremation some Trusts delay procedures for a period up to several weeks during which time the patient can contact the hospital if she changes her mind.
- Trust policies should be clearly stated in any information leaflet provided to the patient prior to discharge from the hospital.

Documentation

In addition to the normal documentation required for discharge and review arrangements the following action should be taken as appropriate:

- A Certificate of Confirmation of Miscarriage should be issued to the patient and other appropriate professionals.
- Inform local co-ordinator of CEMACH (Confidential Enquiry into Maternal and Child Health) of fetal loss after 22 weeks of pregnancy (or weight > 400grams if gestation not known).
- Ensure all others involved in care have been notified, e.g. antenatal clinic, GP, community midwife, ultrasound department, parentcraft, social worker.

Organisations for patients

- Advise the patient of the Book of Remembrance and Annual Services, where available.
- Provide information leaflets for patient and family members.
- Provide contact addresses and telephone numbers of regional and local support groups.

Staff Training and Education

- All staff must be aware of protocols for management of miscarriages within the unit.
- All medical staff seeking post mortem consent should be appropriately trained. All medical, nursing and midwifery staff should fully understand what is involved in a post mortem examination.
- All staff attending a patient who has experienced miscarriage, must have guidance and training in how to care for, and support families, who have suffered the loss of their baby.
- There should be regular audit and arrangements for risk management.

Section III – Pregnancy loss at 24 weeks gestation or later.

Care and arrangements for patients who deliver a baby of more than 24 weeks gestation with no signs of life (stillbirth).

Trusts should supplement this section in accordance with local needs and circumstances.

Introduction

- This section sets out principles of good practice for the management of patients who deliver a baby of more than 24 weeks gestation with no signs of life (stillbirth).
- The circumstances of a stillbirth may vary widely, from cases in which the patient is aware that the baby has died in utero to occasions where death has occurred close to or during labour/delivery. While the circumstances may vary, the principles of patient management remain the same.

Definition

- The Stillbirth (Definition) Order (Northern Ireland) came into operation on 1 October 1992 (No. 1310 (N.I. 10), Statutory Instruments). A stillbirth means "the complete expulsion from its mother after the 24th week of pregnancy of a child which did not, at any time after being completely expelled or extracted, breathe or show any other evidence of life".
- The World Health Organisation (WHO) definition of a live birth states:

"Complete expulsion or extraction from its mother of a product of conception irrespective of the duration of pregnancy which, after separation, breathes or shows any evidence of life, such as beating of heart, pulsation of cord or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta attached".

Patient Centred Care

- Each patient will have unique needs, which must be recognised and addressed. Respect and understanding for the individual nature of experience is fundamental to care. Decisions must, where possible, be compatible with a patient's wishes, choices and requests.
- Although decisions must be taken by the patient, the participation of her partner and family may be important in decision-making. Where the term 'patient' appears throughout this document it may need to be interpreted as 'the woman and her partner/family'.
- The patient is most likely to appreciate care when it is individualised to her needs, is agreed in consultation with staff, and recognises the emotional aspects of pregnancy loss.

CLINICAL MANAGEMENT

Antenatal Care

- The diagnosis of intrauterine death must be made by a doctor with appropriate experience in obstetric care.
- The options of care should be discussed with the patient in a quiet and private environment. Senior staff should be involved in counselling and adequate time allowed for decision-making.
- Admission should be to an appropriately sited single room if possible.
- The patient should be provided with appropriate verbal and written information about stillbirth.
- A checklist should be developed itemising investigations required.
- It may be considered appropriate to discuss the possibility of a post mortem examination at this stage.
- Ensure all others involved in care have been notified, e.g. antenatal clinic, GP, community midwife, ultrasound department, parentcraft, social worker.
- If, prior to delivery, a patient wishes to return home to make family arrangements this should be facilitated providing her health is not at risk.
- Cancel outstanding appointments.

Admission and Delivery

- Continuity of care should be provided by senior staff. Discussions with the patient should cover family support during delivery and care during labour and delivery.
- Healthcare professionals should support patients through the difficulties associated with giving birth to a baby who has died.
  Choices for analgesia should be discussed carefully. It should be explained that pain relief will be provided but that strong sedation may block memories that patients later wish they could recall.

Postnatal Care

- Ensure the patient has privacy and continuity of care from experienced staff. The patient should be accommodated in areas separate from other postnatal patients.
- Patients should be provided with appropriate information to prepare them for the baby's appearance, which will be different to that of a liveborn baby.
- Patients who wish to photograph, hold or spend time with their dead baby should be facilitated in doing so.
- Discuss options for spiritual support. Inform clergy/religious advisor according to the patient's requests.
- Discuss Baptism/naming ceremony with the patient.
- Discuss photography with the patient, distinguishing between clinical and personal photographs.
- Ensure baby is dressed in clothes of patient's choice, or other appropriate baby clothes.
- Offer to provide mementos, including: hand/footprints; photographs; cot card; ID bands; lock of hair.

Discharge Home

- Ensure investigation checklist is complete.
- Be aware that early discharge is often requested.
- The Consultant-in-charge should discuss the pregnancy/outcome and any preliminary post mortem examination results with the patient before discharge.
- Postnatal care should be offered by the community midwife and GP. A follow-up visit by the hospital midwife or other professional involved in the patient's care may be offered within six weeks of the loss.
- Referral to the Regional Genetics Centre should be discussed with the patient if the stillbirth is thought to have a genetic cause.
- A timely discharge letter should be written by senior staff to the GP, and where relevant to the referring clinician.
- Follow-up arrangements should be discussed with the patient, her wishes documented and the necessary arrangements made by the consultant.
- The baby should be discharged from the Mortuary. If other arrangements exist, e.g. from a "Quiet Room", the Mortuary must be notified before discharge.

Hospital Review

- Review by the Consultant-in-charge should take place in an environment which provides privacy and gives adequate time for discussion.
- Ensure all relevant notes, results of investigations and if applicable the full post mortem report are available for the consultation.
- The patient should be advised about her obstetric care in any future pregnancy, and the plan of care should be clearly documented.
- Check all investigations are complete before arranging review appointment.

Post Mortem examination

- Notify the Mortuary and complete relevant documentation.
- Valid consent should be obtained in keeping with the guidance contained in *Post Mortem Examinations: Good Practice in Consent and the Care of the Bereaved.*
- If a post mortem examination is required the patient should be provided with the booklet, *Information for Parents: Hospital Post Mortem Examination of a Baby.*
- Consent should be obtained as detailed in *Consent Form for a Hospital Post Mortem Examination of a Baby.*

- Medical staff should be involved in providing information, obtaining consent and counselling patients as appropriate.
- If consent for a post mortem examination is obtained, contact the Paediatric Pathology Service to arrange the examination. Contact the Mortuary to arrange transport to and from the Royal Hospitals in accordance with agreed guidance.

The Placenta

- The placenta should be sent for histology.
- If the baby is to have a post mortem examination performed, the same pathologist should examine the placenta.

Burial/Cremation

- Consent for burial/cremation should be obtained as detailed in *Consent Form for a Hospital Post Mortem Examination of a Baby.*
- Patients may request the hospital to make arrangements for the burial/cremation.
- Following written consent for the hospital to arrange burial/cremation some Trusts delay procedures for a period of up to several weeks, during which time the patient can contact the hospital if she changes her mind.
- Trust policies should be clearly stated in any information leaflet provided to the patient prior to discharge from the hospital.

Documentation

In addition to the normal documentation required for discharge and review arrangements the following action should be taken as appropriate:

- Notify the stillbirth.
- Provide the Stillbirth Certificate to the patient.
- Advise the patient about Registration of Birth.
- Inform the local co-ordinator of CEMACH (Confidential Enquiry into Maternal and Child Health).

Organisations for Parents

- Advise the patient of the Book of Remembrance and Annual Services, where these are available.
- Provide information leaflets for patient and family members.
- Provide contact addresses and telephone numbers of regional and local support groups.

Staff Training and Education

- All staff must be aware of protocols for management of patients who have experienced a stillbirth within the unit.
- All medical staff seeking post mortem consent should be appropriately trained. All medical, nursing and midwifery staff should fully understand what is involved in a post mortem examination.
- All staff attending a stillbirth must have guidance and training in how to care for and support families who have suffered the loss of their baby.
- There should be regular audit, including perinatal meetings and arrangements for risk management.

Section IV - Loss of a neonate

Care and arrangements for patients who deliver a baby that dies within the neonatal period.

Trusts should supplement this section in accordance with local needs and circumstances.

Introduction

- This section sets out principles of good practice for the management of patients whose baby dies in the neonatal period.
- The circumstances of a neonatal death may vary widely, from cases in which the patient is aware that the baby has a serious abnormality incompatible with life, to occasions where the death occurs unexpectedly shortly after delivery, and other cases in which there is a death in the first 28 days of life. While the circumstances may vary, the principles of patient management remain the same.
- The focus of this document is the care of a patient for whom a neonatal death is inevitable. If death occurs suddenly within the first few days or weeks of life, the opportunity to discuss events and prepare the patient may be limited. In such cases particular attention should be focused on providing effective patient centred-care in the most appropriate setting.

Definitions

- The World Health Organisation (WHO) definition of a live birth states:
  "Complete expulsion or extraction from its mother of a product of conception irrespective of the duration of pregnancy which, after separation, breathes or shows any evidence of life, such as beating of heart, pulsation of cord or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta attached".
- The neonatal period refers to the first 28 days of life.

Patient Centred Care

- Each patient will have unique needs, which must be recognised and addressed. Respect and understanding for the individual nature of experience is fundamental to care. Decisions must, where possible, be compatible with a patient's wishes, choices and requests.
- Although decisions must be taken by the patient, the participation of her partner and family may be important in decision-making. Where the term 'patient' appears throughout this document it may need to be interpreted as 'the woman and her partner/family'.
- The patient is most likely to appreciate care when it is individualised to her needs, is agreed in consultation with staff, and recognises the emotional aspects surrounding the loss of a baby.

CLINICAL MANAGEMENT

Antenatal Care

- A fetal abnormality incompatible with survival may have been diagnosed by ultrasound. If so, this provides time for the preparation of the patient and staff. The developments in fetal anomaly scanning services enhance the opportunity for diagnosis, preparation and decision-making and place of confinement (e.g. conditions which may require intensive care or neonatal surgery).
- Paediatric advice should be available, if appropriate, prior to admission/delivery. In some circumstances it may be relevant to discuss post mortem examination at this stage.
- Ensure all others involved in care have been notified, e.g. antenatal clinic, GP, community midwife, ultrasound department, parentcraft, social worker.
- Cancel outstanding appointments.

Admission and Delivery

- In cases of extreme prematurity it may be apparent that, although the baby may be born alive, early death is inevitable. Following discussion with the patient an experienced obstetrician/paediatrician should advise on which resuscitative procedures are appropriate.
- Ensure patients have privacy and continuity of care from experienced staff.
- Discuss options for spiritual support with the patient.
- A checklist should be developed itemising investigations required.
- Privacy and support from appropriately trained staff is essential.
- Where early neonatal death is inevitable, patients need to be informed that the baby may have a heartbeat and make breathing efforts for some time. Staff should assure patients that they will make the baby as comfortable as possible.
- Healthcare professionals should support patients through the difficulties associated with giving birth to a baby who will almost certainly die shortly after birth. Choices for analgesia should be discussed carefully. It should be explained that pain relief will be provided but that strong sedation may block memories that mothers later wish they could recall.
- Continuity of care should be provided by senior staff. Discussions with the patient should cover family support during delivery, and care during labour and delivery.

Postnatal Care

- Ensure the patient has privacy and continuity of care from experienced staff. The patient should be accommodated in an area separate from other postnatal patients.
- Arrangements will vary depending on whether the baby is being cared for in the labour ward or the neonatal unit. Decisions regarding management should be taken by a senior paediatrician in consultation with the patient.
- Following the baby's death arrangements may vary depending on whether death was predicted, inevitable, sudden or unexpected. Investigations should be tailored to individual circumstances.
- Patients who wish to photograph, hold or spend time with their dead baby should be facilitated in doing so.
- Discuss options for spiritual support. Inform clergy/religious advisor according to the patient's requests.
- Discuss Baptism/naming ceremony with the patient.
- Discuss photography with the patient distinguishing between clinical and personal photographs.
- Ensure baby is dressed in clothes of patient's choice, or other appropriate baby clothes.
- Offer to provide mementos, such as a booklet containing: hand/foot-prints; photographs; cot card; ID bands; lock of hair.
- Notify the Mortuary and complete relevant documentation.
- The baby should be discharged from the Mortuary. If other arrangements exist, e.g. from a "Quiet Room", the Mortuary must be notified before discharge.

Discharge Home

- Ensure investigation checklist is complete.
- Be aware that early discharge is often requested.
- The Consultant Obstetrician and Paediatrician should discuss pregnancy/outcome and any preliminary post mortem examination results with the patient before discharge.
- Postnatal care should be offered by the community midwife and GP. A follow-up visit by the hospital midwife or other professional involved in the patient's care at the time of delivery may be offered within six weeks of the death.
- Referral to the Regional Genetics Centre should be discussed with the patient if the neonatal death is thought to have a genetic cause.
- A timely discharge letter should be written by senior staff to the GP, and where relevant to the referring clinician.
- Follow-up arrangements should be discussed with the patient, her wishes documented and the necessary arrangements made by the consultant.

Hospital Review

- Review by the Consultant Obstetrician and/or Paediatrician in-charge should take place in an environment which provides privacy and gives adequate time for discussion.
- Ensure all relevant notes, results of investigations and if applicable the post mortem report are available for the consultation.
- The patient should be advised about her obstetric and neonatal care in any future pregnancy and the plan of care should be clearly documented.
- Check all investigations are complete before arranging review appointment.

Post Mortem Examination

- Notify the Mortuary and complete relevant documentation.
- Valid consent should be obtained in keeping with the guidance contained in *Post Mortem Examinations: Good Practice in Consent and the Care of the Bereaved.*
- If a post mortem examination is required the patient should be provided with the booklet, *Information for Parents: Hospital Post Mortem Examination of a Baby.*
- Consent should be obtained as detailed in *Consent Form for a Hospital Post Mortem Examination of a Baby.*
- Medical staff should be involved in providing information, obtaining consent and counselling patients as appropriate.
- If consent for a post mortem examination is obtained, contact the Paediatric Pathology Service to arrange the examination. Contact the Mortuary to arrange transport to and from the Royal Hospitals in accordance with agreed guidance.

Coroner's Cases

- If a coroner's post mortem examination is required the patient should be provided with the booklet, *Information for Relatives: Coroner's Post Mortem Examination.*
- Consent for further use of tissue samples, genetic material and images can be sought using the *Form for Further Use of Material Retained Following a Coroner's Post Mortem Examination.*
- Informed consent for the further use of tissue samples, samples for genetic testing and images should be obtained in keeping with the guidance contained in *Post Mortem Examination: Good Practice in Consent and the Care of the Bereaved.*

Burial/Cremation

- Consent for burial/cremation should be obtained as detailed in *Consent Form for a Hospital Post Mortem Examination of a Baby.*
- Patients may request the hospital to make arrangements for the burial/cremation.
- Following written consent for the hospital to arrange burial/cremation some Trusts delay procedures for a period of up to several weeks, during which time the patient can contact the hospital if she changes her mind.
- Trust policies should be clearly stated in any information leaflet provided to the patient prior to discharge from the hospital.

Documentation

In addition to the normal documentation required for discharge and review arrangements, the following action should be taken as appropriate:

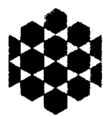
- Notify the birth.
- Notify the death.
- Advise the patient about Registration of Birth and Death.
- Inform the local co-ordinator of CEMACH (Confidential Enquiry into Maternal and Child Health).

Organisations for Parents

- Advise the patient of the Book of Remembrance and Annual Services, where these are available.
- Provide information leaflets for patient and family members.
- Provide contact addresses and telephone numbers of regional and local support groups.

Staff Training and Education

- All staff must be aware of this protocol for neonatal deaths within the unit.
- All medical staff seeking post mortem consent should be appropriately trained. All medical, nursing and midwifery staff should fully understand the post mortem examination.
- All staff attending a neonatal death must have guidance and training in how to care for and support families who have suffered the loss of their baby.
- There should be regular audit, including perinatal meetings and arrangements for risk management.



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