University Hospitals Sussex
NHS Foundation Trust

# Pregnancy Loss > 14 Weeks

Maternity Protocol: MP073

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| | **GP001**: Early Pregnancy Unit Clinical Guidelines |
| | Gynaecology- management of miscarriage |

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## Key Principles

A protocol is a set of measurable, objective standards to determine a course of action. Professional judgement may be used in the application of a protocol.

## Scope

This protocol applies to:

- Any woman experiencing a fetal loss (at any gestation after 14 weeks) including TOPs, mid-trimester losses, stillbirths or neonatal death.

## Responsibilities

*Midwives, gynaecology staff and medical staff:*

- To access, read, understand and follow this guidance
- To use their professional judgement in application of this protocol

*Management Team:*

- To ensure the protocol is reviewed as required in line with Trust and National recommendations
- To ensure the protocol is accessible to all relevant staff

# Introduction

This document provides guidance on maternity management of women and their families through a pregnancy loss. The maternity service care for women after 14 weeks of pregnancy - prior to that gestation, care is given by the gynaecology service, please refer to management of miscarriage protocol for under 14 weeks.

The protocol has been divided into two parts to assist in the care for these women. Part one outlines the clinical care; Part Two details the support and arrangements families may need.

Women can present in a variety of ways:

- Spontaneous miscarriage - non-viable fetus below 24 weeks
- Intrauterine death – >24 weeks no fetal heart detected.
- Termination of pregnancy
- Loss of one or more babies in a multiple pregnancy

This guideline combines and replaces maternity guidelines,

- *MP073 Management of pregnancy losses above 14 weeks* (2015)
- *MP074 Sensitive handling disposal of products of conception and non-viable fetus under 23+6 weeks of gestation* (2012)

And should be read in conjunction with gynaecology guidelines,

- *GP001 Early Pregnancy Unit Clinical Guidelines* (2016)
- *GP010 Termination of Pregnancy (Under 14 Weeks)* (2016)
- GP001 Management of Miscarriage

# Part One

## Section One- Over 14 weeks

Clinical and emotional care for pregnancy losses are primarily the same regardless of gestation. The difference is with the paper work and registering baby. Therefore this guide is laid out for all gestations over 14 weeks and breaks down the differences under the paperwork section.

### An unexpected intrauterine death over 14 weeks

1.0 Inform the Registrar / Consultant on call.

1.1 Perform or arrange an ultrasound scan to confirm no heart beat and presentation.

1.2 When diagnosing a fetal loss if practitioner is in any doubt a second opinion should be immediate this is to include calling in a consultant.

1.3 Women should be prepared for the possibility of passive fetal movement. If the woman reports passive fetal movement after the scan to diagnose IUD, a repeat scan should be offered.

1.4 If the woman is unaccompanied, an immediate offer should be made to call her partner, relatives or friends.

1.5 Discussions should aim to support maternal/parental choice and should be supported with written information- give SANDS Bereavement Pack.

1.6 Obtain appropriate checklist (Under 24, Over 24 or TOP) and commence.

1.7 Laboratory blood tests to be taken as per relevant checklist, and documented.

1.8 As a minimum a kleihauer must be taken for all women and sent on the day of diagnosis. This is to identify if feto-maternal haemorrhage is the cause and enables sufficient anti- D to be administered within 72 hours. If feto-maternal haemorrhage is identified repeat kleihauer in 48 hours.

1.9 Inform pregnancy loss midwives by email on the day of diagnosis, this will enable support for women prior to induction.

1.10 Discussions to be had with woman during this time

- Options available including expectant management (Section Three)
- Mode of delivery (Section Two)
- Induction of labour process(Section Four)
- Post Mortem – supported with written literature- SANDS deciding on Post mortem (Section Fourteen)

1.11 Ensure contact details for pregnancy loss midwives are given to parents. (Appendix1)

# Section Two- Mode of delivery

Recommendations about labour and birth should take into account the mother's preferences as well as her medical condition and previous intrapartum history. Vaginal birth is the recommended mode of delivery for most women, but caesarean birth will need to be considered with some If the woman is 24 weeks gestation or more and requests delivery by caesarean section, there should be a full discussion about the risks of caesarean section and the impact on any future pregnancies. If after full discussion of risks the woman wants to proceed with a caesarean section, her wishes should be respected, after discussion with the consultant on-call.

# Section Three- Expectant Management

3.0 If expectant management is chosen this should be supported as long as there are no signs of complications such as sepsis, pre-eclampsia, abruption or ruptured membranes.

3.1 85% of women with an IUD labour spontaneously within three weeks of diagnosis.

3.2 She should be advised that she is at an increased risk of complications if the delay is prolonged (such as sepsis and disseminated intravascular coagulation DIC).

3.3 If the delay is more than 48 hours, the woman should be offered twice-weekly blood tests for DIC and warned that the risk of developing DIC increases with continuing expectant management: 10% within 4 weeks after the date of late IUFD, rising to 30% thereafter.

3.4 The woman should be told that she may continue to experience passive fetal movement

3.5 Women contemplating prolonged expectant management should be advised that the appearance of the baby may deteriorate, and the value of post mortem may be reduced.

# Section Four- Inducing labour

4.0 For an intrauterine death above 14 weeks induction of labour should be arranged in consultation with the woman and labour ward coordinator.

4.1 A full explanation should be given to ensure that the woman is aware of the procedure, details of when she should return to labour ward and the contact number of labour ward should she have any concerns.

4.2 Prescribe the misoprostol and mifepristone at same time, the drug chart needs to be sent to Pharmacy for the misoprostol to be dispensed prior to returning for induction. The dosage will depend on gestation and whether the woman has previously had a caesarean section. (see flow charts below)

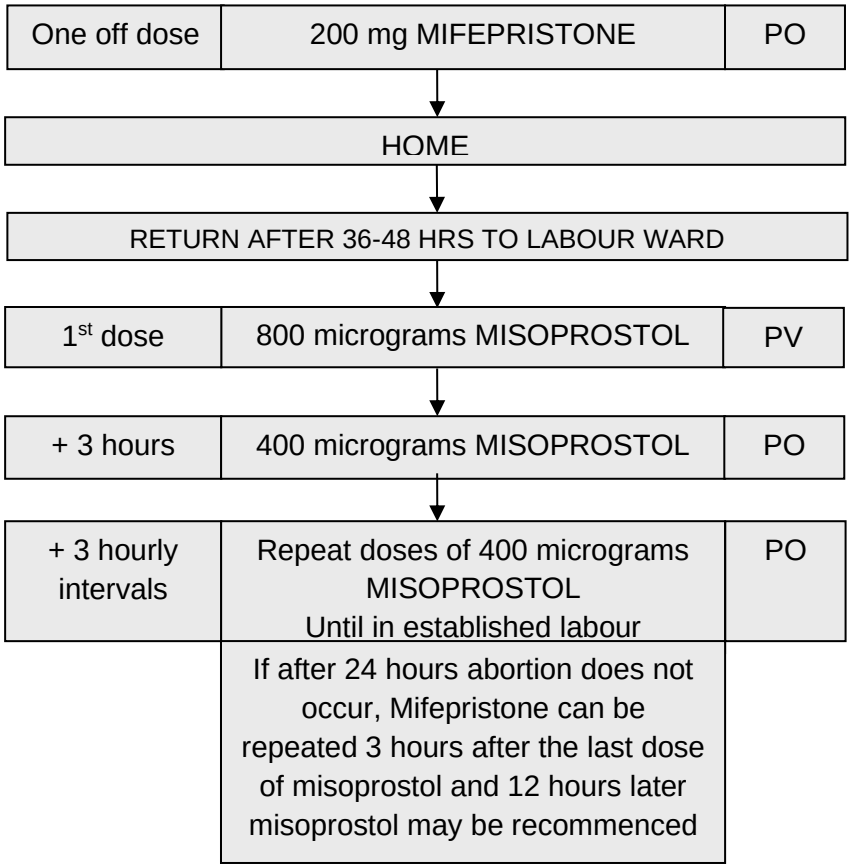
4.3 Appropriate analgesia MUST be prescribed with the misoprostol ready for admission.

4.4 If the woman vomits within 30 minutes of taking mifepristone give an antiemetic and repeat mifepristone does 30 minutes later.

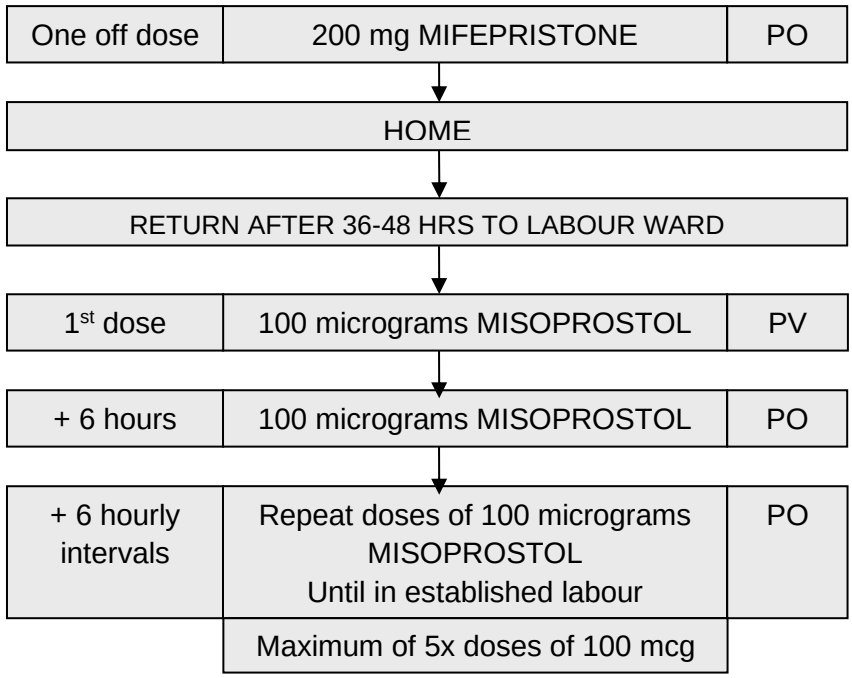
4.5 If gastrointestinal side effects occur with oral misoprostol doses can be administered vaginally as side-effects are less with this route of administration.

# Section Five- Mifepristone & misoprostol

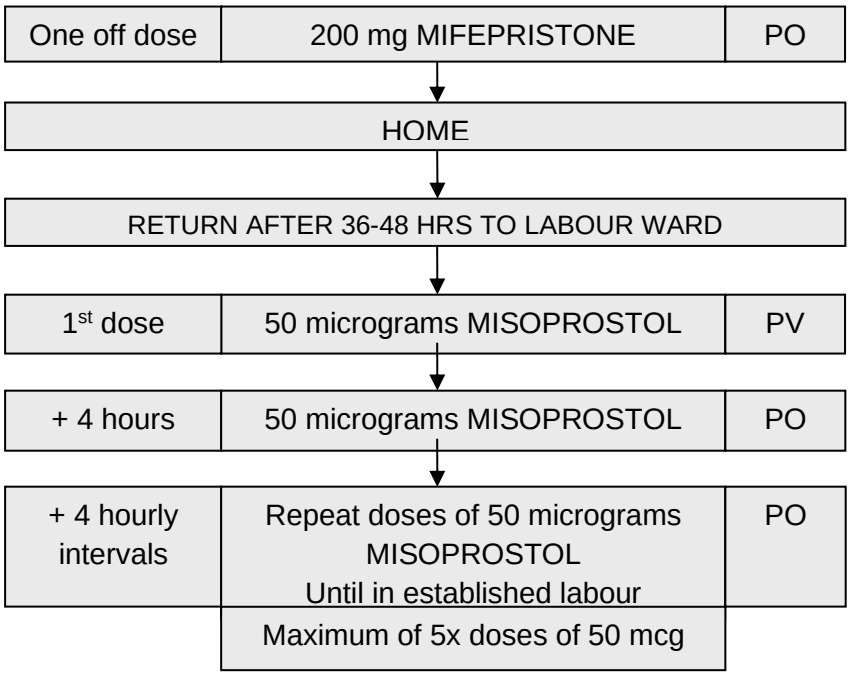
### 5.0 Flow chart for up to 23+6 weeks




### 5.1 Flow chart for 24 to 26+6



**5.2 Flow chart for 27 weeks and above**




# **Section Six-** Previous Caesarean

6.1 A discussion of the safety and benefits of induction of labour should be undertaken by a consultant obstetrician. Options include the use of mifepristone alone, or the use of a lower dose of misoprostol. Women undergoing VBAC should be closely monitored for features of scar rupture.

6.2 Drug regime should be discussed with the Consultant on call and documented in maternity notes.

6.3 Oxytocin augmentation can be used for VBAC, but the decision should be made by a consultant obstetrician.

6.4 Women with 3 or more previous lower segment caesarean sections or a classical caesarean section should be informed that a birth by LSCS is recommended.

6.5 If a Women chooses in line with her priorities and preferences a repeat LSCS a consultant should attend for the procedure

# **Section Seven-** On Admission/during induction

7.0 Prepare the room/bereavement room and remove unnecessary monitoring equipment and the cot. (Ideally the room is away from other pregnant women and babies)

7.1 Collect relevant bereavement pack and continue or commence checklist, start to complete (Master copy of checklist can be found on bereavement drive- all band 7 have access).

7.2 Ensure induction drug regime prescribed and ordered (Section five) commence induction. If TOP, prior to induction ensure relevant paperwork complete (See Flowchart)

7.3 Discuss process with parents ensure understanding and fully informed of options and have received SANDS information pack.

7.4 During the admission, the following must be discussed (when relevant) and documented on the checklist and in the maternity notes:

- **Birthplan:** Do they wish to see baby at birth, document and ensure verbal hand over between professionals.
- **Creating memories**: parents' wishes regarding seeing, holding and naming the baby.(For more detail see Part Two-E)
- **Post mortem:** Although PM is recommended it is parents' choice. Support discussion with SANDS deciding on PM leaflet. If would like pm attempt to complete consent form prior to delivery. (Section Thirteen)
- **Funeral arrangement-** Talk about options, ensure parents have received SANDS leaflet. Explain the pregnancy loss midwives can assist with this. (Section 15 or Part Two- I)
- **Chaplaincy services**- offer even if non-religious (Part Two- D and Appendix 2)

# **Section Eight -** Care in labour

8.0 Refer to MP035: Care of Women in Labour- for routine labour care.
No fetal monitoring equipment, contractions to be manually palpated if necessary.

8.1 For women colonised with Group B Streptococcus prophylactic antibiotics are not required.

# **Section Nine -** Analgesia Options

9.0 Patient should be written up for liberal analgesia, as they may find labour and delivery insufferably harder.

9.1 Discuss with the anaesthetist on admission ensure they are aware of the situation and allow them to assess for coagulopathy and or sepsis.

9.2 Offer oral analgesia/ Entonox in the normal way if patient wishes

9.3 Diamorphine and morphine preferred over pethidine as they have greater analgesic qualities and longer duration of action.

9.4 Regional anaesthesia should be available- Epidural Analgesia as per MP042 Epidurals in Labour protocol

9.5 Patient Controlled Analgesia System

- Prescribed by the anaesthetist and prepared by recovery staff from level 5. Patients with a PCA require nasal oxygen and hourly respiratory rate measurement- commence PCA chart.

9.6 If labour ward anaesthetist not available

- RSCH- midwife to liaise with third on call on bleep 8224.

- PRH- Midwife to liaise with bleep holder 6442 (this may not be covered by an anaesthetist but must be first point of call.)
- For both sites if the delay is anticipated to be more than one hour consultant anaesthetist to be contact in line with anaesthetic protocol.

9.7 Birthing pool can be considered where no contraindications exist.

# Section Ten - Birth/ Delivery

10.0 Ensure women's wishes are respected- midwife prepared in situations such as where the woman does not wish to see baby.

10.1 Baby tone is likely to be poor- carefully support parents when handling baby

10.2 Be cautious when identifying the sex of babies of early gestations. Ensure that parents are aware if you are unsure. If parents opt for a post-mortem the sex will be confirmed within the findings.

# Section Eleven - Third stage

11.0 Active management is recommended 10 units Oxytocin IM for all women.

# Section Twelve - Postnatal

12.0 Parents should be supported to see, hold, wash and dress their baby if that is their wish

12.1 The cold cot should be used for all babies either in the Sunset room or with the parents depending on the situation.

12.2 Parents should be offered to take their baby home and supported with their wishes (Section Seventeen and Part Two-H.)

12.3 Create memories with parents- give 4louis box and Oscars wish foundation bag. Take hand/ foot prints, photos, cot cards all should be offered to parents and if declined stored in hospital notes. (Part two section E- for more details).

12.4 Unless the mother's health dictates otherwise, the length of stay should be flexible according to her needs.

12.5 Inform relevant professionals of pregnancy loss

- Call GP
- Email- Pregnancy loss information sharing- this is a global distribution list (or click this link and check names in outlook) and will inform pregnancy loss midwives, Postnatal team, antenatal clinic and sonographers, please include:
  - Mothers: Name, Hospital number
  - Parity / gestation

- NHS number (baby) if applicable
- short summary of events

- Email- For babies born with signs of life please email Child Health Information Services to notify them of the death on sc-tr.cchis@nhs.net, please include:
  - Mother's/Parent's: Name, Hospital number
  - Parity/gestation
  - NHS number (baby)
  - Short summary of events

12.6 Offer Cabergoline 1mg orally following birth for suppression of lactation. It should not be given to women with hypertension or pre-eclampsia.

12.7 Provide emotional support and relevant information about support groups/counselling to parents in verbal and written format- pregnancy loss midwives can help with this. (Part Two-J and Appendix 3)

12.8 Ensure parents cultural needs are met (Part two-D)

12.9 Complete a Datix- for reviewing purposes.(Part Two- M)

12.10 Ensure checklist complete and 'fresh eyes' check of the notes with labour ward coordinator.

12.11 The notes should be placed in the pregnancy loss notes cupboard on the labour ward at RSCH and in the hummingbird room at PRH. The pregnancy loss midwife will ensure the paperwork is complete and send the notes to coding.

12.12 Ensure support is offered to staff (See Part Two- L and Appendix 4)

# Section Thirteen – Placenta

13.0 **If NOT for Post mortem** - Send to histology dry in white pots- labelled with mothers details attach histopathology for (Appendix 5)

13.1 **If FOR Post mortem -** send placenta dry in white pot with the baby to the mortuary- labelled with mothers details attach histopathology

# Section Fourteen - Post mortem examination

14.0 All women should be offered full post-mortem examination over 14 weeks to help explain the cause of death.

14.1 The SANDS information leaflet 'Deciding on Post mortem' is to be given to the parents so that they can decide about a post mortem prior to consent taking.

14.2 The post mortem consent form (Appendix 6) must be completed in full and taken by a member of staff trained in consent taking- senior midwife, registrar grade or above. Full details of consent taker must be documented.

14.3 The consent taker must go through the consent checklist prior to taking consent and file in the patients notes.

14.4 Results can take up to 8 weeks however it is important to inform women that baby will be returned to mortuary within 7-10 days- unless exceptional circumstances. The pregnancy loss midwives will inform parents when their baby is back.

14.5 Photocopy consent form. One must be given to parent and one in notes.

# Section Fifteen – Funeral

The options for funeral arrangements should be discussed with parents. The two options are choice of hospital or arrangement of own funeral. Currently each site offers slightly different services (see Part 2-I)

**15.0 Own Funeral**

- Parents should be given list of funeral directors (Appendix 7).
- Pregnancy loss midwives can help with arrangements.
- There is no charge for cremation but there will be a small charge for burial plot
- Parents should be informed that their funeral director should be in touch with the hospital within 30 days to arrange collection of the baby.

**15.1 Hospital funeral** - parents at both sites have 30 days to change their mind.

- RSCH- Parents need to understand there is no service or ashes with hospital cremation at any gestation.
- PRH- Hospital cremations are able to offer parents ashes from 24/40.

# Section Sixteen - Paper work

The flowcharts below outline the relevant paperwork for each gestation. Flowchart 15.1 is the generic paperwork for all losses, and then they are split for specific paperwork.

16.1

**Paperwork for all pregnancy losses**

Bounty suppression form- leave in external mail tray.

Blood Forms- complete relevant and send to lab.

Pregnancy loss information form- fax to Obstetric secretary, leave pregnancy loss midwife copy in purple folder

Histology form if not for PM- Send with placenta to the Lab.

Genetics specimen form- if not for PM. Sent with placenta to guys and St Thomas's

Community MW form- send to CMW office.

Coding form- attach to front of brown folder.

16.2

**Post- Mortem Paperwork**

Doctor/trained MW to complete **PM consent checklist**- file in notes.

Midwife to complete London perinatal pathology network – PM request form- Original with baby copy in notes

Midwife to complete **Perinatal/paediatric PM Referral**-Original with baby copy in notes.

Post mortem consent Form

Complete DR, MW who are trained.

1. Original with baby
2. One for parents
3. Copy in notes

**FAX-** Pm Consent and referral form to guys and St Thomas's- 02071883927.

In Wallet/ envelope- addressed F.AO St Thomas's

- PM consent
- London perinatal Request form
- Photocopy of scans

Send with baby to the mortuary

16.3

## Under 24 weeks

NOT registerable

If born with any signs of life follow- signs of life pathway

Doctor to complete P2 Form

**4 copies**

- **Blue and white copy**- in envelope to mortuary with baby
- **Yellow copy**- to woman
- **Pink copy**- in maternal notes

**Computing:**

**Smart-** N/A
**Oasis**- Birth tab, enter date.
**Smart-** patient management-
Outcome- Non-registerable birth

16.4

## Over 24 weeks

Registerable birth- all babies must be registered

If born with any signs of life follow- signs of life pathway.

Cremation form 9- completed by doctor or midwife. Only side 9 to be complete. Send to mortuary with baby. Place a copy in notes

Stillbirth Certificate- completed by doctor. Original to parents, copy in the notes.

Parents to register baby. A **Certificate for burial/cremation** will be issued. Parents need to give certificate to funeral director if own funeral and mortuary if hospital funeral.

**Computing**

**Spine**- complete generate NHS number
**Oasis**- complete all
**Smart**- complete all.

16.5

**TOP**

Certificate A- Abortion Act 1967

Yellow abortion form: signed by 2 doctors

If born with any signs of life follow- signs of life pathway.

Under 24 weeks- complete relevant paperwork in flow chart

Over 24 weeks- complete relevant paperwork in flow chart

If over 24 weeks- Parents to register baby. A **Certificate for burial/cremation** will be issued. Parents need to give certificate to funeral director if own funeral and mortuary if hospital funeral.

**Computing**

**Follow relevant flow chart regarding gestation**

16.6

**Born Signs of life**

**(At any gestation)**

Doctor must see baby

Doctor to inform the coroner

**Complete Cause of Death Certificate**

Death certificate to be faxed to coroner following agreement

**Woodvale Cremation Form 4**- for all gestations- completed by same doctor as above. NOT part 5. Send with baby to mortuary

Complete **Form A- Notification of Child Death**
Email to CDOP

Child-Death.Overview-Panel@eastsussex.gcsx.gov.uk

Email Child Health Information Services to inform them of the death

sc-tr.cchis@nhs.net

Parents to register birth and death.
A **Certificate for burial/cremation** will be issued. Parents to give certificate to funeral director or mortuary.

**Computing**
**Spine**- complete generate NHS number
**Oasis**- complete all
**Smart**- complete all.

# Section Seventeen - Taking baby home

17.1 Women should be offered to take baby home. (Part Two-H for more details on all areas below)

17.2 Under 23 weeks plus 6 days (no signs of life)

- Property of the parents, parents can take home and do not need to return the fetus
- Complete letter (Appendix 9)

17.3 Over 24 weeks or born with signs of life under 24:

- Women can take their babies home-
- Need to complete 'taking your baby home' (Appendix 8).
- Discussion around deterioration of baby should be discussed sensitively
- Cuddle (Cold) cot is available to be lent to parents from both sites.

# Section Eighteen - Follow up

18.0 Pregnancy loss midwives will follow up women within the first week of discharge. Please ensure they are informed using the information sheets provided in the packs and leaving them in designated hummingbird cupboard (RSCH) or room (PRH). **Please try to ensure you obtain an email address for the parents as this is often the preferred method of contact.**

18.1 The wishes of the woman and her partner should be considered when arranging follow-up.

18.2 Community midwife care should continue- ideally with known antenatal midwife for continuity- Carers should be vigilant for postpartum depression

18.3 An appointment will be made for around 8-10 weeks following delivery regardless of whether a Post Mortem is undertaken.

18.4 The consultant responsible for the follow up will be:

- Antenatal named consultant if one identified
- If no antenatal consultant then the consultant on call at the time of pregnancy loss diagnosis.

18.5 If the consultant on-call at the time of diagnosis was a locum, follow-up will be made with one of the pregnancy loss lead consultants (Jo Sinclair or David Utting)

# Part Two

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This practice guidance is derived from statute and code of practice.

# **Section A -** Legal Definitions: Birth and Death Registration

A stillborn baby is defined in law as "a child which has issued forth from its mother after the twenty-fourth week of pregnancy and did not at any time after being completely expelled from tis mother breathe or show any other signs of life." (Births and Deaths Registration Act 1953 s 441, amended by Stillbirth Definition Act 1992)

- Stillbirth must be medically certified by a fully registered doctor or midwife; the doctor or midwife must have been present at the birth or examined the baby after birth. (Statute)

- HM Coroner must be contacted if there are signs of life or any doubt about signs of life. (Statute)

- Police should be contacted if there is suspicion of deliberate action to cause stillbirth. (Statute)

- Fetal deaths that had clearly occurred before the end of the 24th week but deliver after 24 weeks do not have to be certified or registered. (Code of Practice)

- The baby can be registered as indeterminate sex if uncertain awaiting further tests. (Code of Practice)

- The parents are responsible in law for registering the birth but can delegate the task to a healthcare professional. (Statute)

In the 1990s there was an addition to practice, not a change in law, to avoid registration of babies that might have died in early pregnancy (usually a multiple pregnancy). There is also a discrepancy over babies born before 24 weeks who show signs of life, if recorded as a live birth the parents must register the birth.

**Non-Registerable Births**

Any baby born below 24 weeks gestation and not showing any signs of life does not need to be registered with the registry office.

Parents may find it upsetting that they do not receive legal acknowledgment of their baby in these circumstances. SANDS provide certificates of birth for these baby's (Appendix 10), and many varieties can be found on their website www.sands.org, including those for single parents and same sex parents. Copies are available across site, or may be printed onto coloured paper directly from this guideline.

**Registering a Stillbirth**

Any baby born dead over 24 weeks gestation must be registered as a stillbirth. At the time of birth, a doctor of middle grade or above must complete the stillbirth certificate in full – to include their GMC number. A sticker must be placed in the notes and signed by the doctor to confirm this has been filled out in full and instructions have been given to parents (Stickers are kept with Stillbirth certificates at both sites – please inform pregnancy loss midwives if unavailable).

Parents should be supported to understand that they are responsible for registering their baby's stillbirth within 42 days. Healthcare providers should check their understanding of this before discharging from hospital.

When the parents have registered the stillbirth, they will be given a certificate which they must give to their funeral director (If they're having their own funeral) or the bereavement office (if they are having a hospital cremation). This will allow the baby's body to be released from the hospital for funeral.

**Registering a Neonatal Death – Including babies born with signs of life at ANY gestation**

If a baby is born alive and lives for any period of time, the birth and death must be registered, irrespective of the baby's gestation. At the time of death, a doctor of middle grade or above must complete the death certificate in full – to include their GMC number. A sticker must be placed in the notes and signed by the doctor to confirm this has been filled out in full and instructions have been given to parents (Stickers are kept with death certificates at both sites – please inform pregnancy loss midwives if unavailable).

It is the doctors responsibility to inform the coroner of the death at the time of the event (A coroner is on call 24/7 and available via switchboard at both sites). The hospital doctor and the coroner must agree on the appropriate wording of the death certificate, this is usually done verbally and confirmed by fax.

Parents should be advised that the death should be registered within five working days, except in exceptional circumstances (e.g. if maternal condition prevents). The birth and death may be registered at the same appointment.

When the parents have registered the death, they will be given a certificate which they must give to their funeral director (If they're having their own funeral) or the bereavement office (if they are having a hospital cremation). This will allow the baby's body to be released from the hospital for funeral.

# **Section B –** Going home after Diagnosis

Most women will be advised to go home after their initial assessment and administration of Mifepristone. Women should be given the leaflet "Pregnancy loss – giving birth" )Appendix 20) prior to this, and the midwife should ensure she has a clear understanding of when to return.

The pregnancy loss midwives should be informed of the loss by email, and will endeavour to contact the woman during this period to make introductions and offer support. This may not always be possible; therefore it is advisable to offer advice to parents about how they may cope with this difficult period of time, for example, arranging clothing/blankets/keepsakes that they may like to bring in for their baby. Advise women to bring snacks and home comforts if they wish.

Ensure women are encouraged to contact the maternity unit with any worries during this time, and make them aware that they are welcome to return to the hospital if they feel they cannot cope at home.

See section C – religious and cultural beliefs. It may a good time for families to access the hospital chaplain for telephone support at home. The chaplain may be able to make plans for a blessing if this is their wish, or may just be a listening ear. They are a very valuable resource and are happy to be contacted in these circumstances. Ensure parents receive the information leaflet and are advised that this service is available regardless of religious or cultural beliefs.

The midwife should also ensure that the woman is advised to call the maternity unit if she experiences any of the following:

- Onset of contractions
- Spontaneous rupture of membranes
- Feeling unwell

# **Section C -** Understanding Grief

Grief and mourning are powerful emotions and behaviours that can be disturbing both for the bereaved person and for all midwives, doctors, and support staff. As with all human emotions, grief is made up of a complex combination of feelings, physical sensations, thoughts and behaviours

Understanding the ways in which grief manifests itself and how this changes over time can be helpful. It can help normalise what might otherwise seem like unusual behaviour and experiences. It can also be useful to have some idea about when and how things are likely to change.

The course of grief has been broken down into different stages or phases, and the process involves a number of tasks for the mourner. This process is not smooth or predictable and some people never reach acceptance. Many factors influence the course of grief but the general path and direction is the same.

The four phases of Grief:

| Phase | Features | Task |
|---|---|---|
| **DENIAL** | Shock; disbelief; sense of unreality, questioning results and treatment | To accept the reality of the loss<br>Helped by: traditional rituals, involvement of family in care of baby after death. |
| **PAIN/DISTRESS** | Hurt; anger; guilt; searching; worthlessness | To experience the pain of grief<br>Helped by: understanding that different people grieve in different ways and for different periods of time. |
| **REALISATION** | Depression; apathy; exhaustion; tearfulness; experiencing the loved one: smelling, hearing, seeing, feeling | To adjust to life without the person<br>Helped by acceptance that changeable emotional states are normal. |
| **ACCEPTANCE** | Readiness to engage in new | To relocate emotional |

| | | |
|---|---|---|
| | activities and relationships | energy elsewhere |

When parents leave the hospital following the death of their child they will have only just started on their journey through grief. Staff can help prepare them for this by mentioning:

• Triggers – sights, sounds and smells associated with their pregnancy and baby may make them unexpectedly distressed. This is very natural and thinking ahead can sometimes help parents cope better. Families are often prepared for the difficulty of seeing unused baby clothes and equipment but may not have thought about how they might be affected by other things such as songs that were popular during their confinement or smells of toiletries they used during pregnancy. Women who go on to try for another baby are often surprised by how distressed they can become with the onset of a period.

• Anniversary effects – for parents who have lost a child the year is peppered with meaningful dates. These include not only the baby's date of birth and death but also special times of year such as Christmas and Mother's Day. It is helpful for parent to know that it is not unusual to feel more upset around these times of year.

• Other losses and separations – routine experiences such as being left alone when a partner returns to work or goes away for the first time following the death of a baby can reawaken feelings of loss and abandonment.

• Differences -- in grieving and seeking comfort and consolation can be trying for some relationships. Couples need to be aware that their way of dealing with their baby's death may not be the same as their partner's. It does not mean that they do not feel as sad about their loss. Similarly couples may differ in their need for physical comfort. On the one hand they may want the comfort of being held closely and the reassurance of still being attractive to their partner. On the other hand they may not want this to move onto intercourse. If couples are not aware of these differences misunderstandings can occur and relationships suffer

# **Section D -** Religious and Cultural Beliefs

1. Patients admitted to the BSUH NHS Trust come from a variety of ethnic and religious backgrounds. In the event of a death, grief may easily be increased if staff members do not comply with the dictates or preferences of individual religious or cultural beliefs.
2. Muslim, Jewish and other religions' relatives may request that the death be processed immediately. Guidance for this is via the chaplaincy contact list or via switchboard (Appendix 10)

3. The trust offers 24 hour access to an on-call chaplain, who may contacted via switchboard.
4. Chaplaincy is an invaluable resource regardless of religious denomination, and should be offered to all women/families affected by bereavement.
5. There is a Book of Remembrance in the chapel. This is accessible 24 hours a day and is available to all parents. If parents complete the book of remembrance they will be informed of memorial services arranged by the chaplaincy team.
6. See Appendix B.

# **Section E -** Creating Memories

Many parents feel a strong desire to cherish and remember their baby and to preserve his or her continuing presence in their lives. Physical items connected to their baby may help to confirm the reality of his or her short existence and provide comfort as well as a focus for their grief. (SANDS 2016)

Some parents may only wish to see or hold their baby for a short period of time; however others may wish to hold or keep the baby in the room with them for longer or overnight. Babies should be placed in cuddle cots (provided at each site) when they spend time with their parents and family. Parents can take as long as they need with their baby and a cold cot can be set up in their room. They will be placed into a casket when they are subsequently taken to the mortuary.

Carers should avoid persuading parents to have contact with their stillborn baby, but should strongly support and facilitate such desires when expressed. SANDS (2016) recommend that parents are offered opportunities more than once, as they may change their mind at various stages.

Parents who are considering naming their baby should be advised that after registration a name cannot be entered at a later date, nor can it be changed. If parents do decide to name their baby, all carers should refer to the baby by name where possible, including at follow–up meetings.

Parents should be offered, but not persuaded, to retain artifacts of remembrance.

Verbal consent should be sought from the parents and information governance regulations should be complied with for clinical photography and their storage in the notes.

Memory boxes are provided by SANDS and 4LOUIS. Smaller boxes are provided for losses < 24/40; however please use your discretion when deciding which box to offer.

**A. Hand & Foot prints**

Inkless wipes and paper are provided at both RSCH and PRH sites and are stored in the pregnancy loss room on each labour ward. Please inform the pregnancy loss midwives if any restocking is required.

It is easier to achieve good quality prints if taken by two people. One person should hold the hand/foot steady and the other may 'roll' the paper onto it.

Please secure in an envelope with the woman's hospital number in the hospital notes if parents do not wish to have them, as may change their mind in future.

Our memory boxes are provided by SANDS and 4LOUIS. These contain clay impression sets which can be used for hand and foot prints in addition to the paper prints.

**B. Photographs**

Cameras and colour printers are provided at both sites. Individual SD cards are provided within the memory boxes. These can be given to parents in addition to prints.

Take as many photographs as you feel appropriate. Blankets, knitted nests, clothes and hats are available in the pregnancy loss rooms at each site. Please inform the pregnancy loss midwives if there is low stock of anything you need.

Offer to take photographs of parents with their baby if they are spending time with them. These moments are precious and should be captured if possible.

Some, but not all Bounty photographers are able to assist with photography. During working hours, approach bounty staff directly if they are on site.

**C. Other Mementoes**

- A lock of hair if possible – place in small jewelry box provided.
- Name bands
- Cot card
- Certificate of birth for non-registerable babies (if born under 24 weeks)
- Teddy's – give one to parents and one to stay with baby.

**D. Chestnut Tree House Neonatal Services**

Chestnut Tree House is a children's charity providing hospice care services and community support for children and young people with progressive life-shortening conditions throughout East and West Sussex, Brighton and Hove and South East Hampshire.

When a baby dies, families are offered the use of the bereavement suite, 'Stars'. There is a cool room where their baby can remain for a period of time. Support is offered whilst planning a funeral, in saying their goodbyes and continues with optional counselling and remembrance events in the future.

Midwives may refer families to Chestnut Tree House in instances where parents and extended family members would like to spend some extra time with their baby, but may not wish to return to their own home or stay in hospital.

To make a referral, call the Community Nurse Manager on 01903 871803, or contact the hospice via their switchboard on 01903 871800.

The hospice is located at: Dover Lane
Arundel
West Sussex
BN18 9PX

Nb: if the baby is over 24 weeks gestation, it will be necessary to liaise with the mortuary for advice to arrange the release of the baby from our hospitals.

Below 24 weeks gestation (if not born showing signs of life), it is acceptable to release the baby directly from the maternity unit using form 'release of baby's body to parents'

The bereavement midwives will be able to help you with this.

# **Section F -** Pregnancy Loss in Multiple Pregnancy

Families who have lost a baby from a twin/ triplet pregnancy face the difficult challenge of dealing with the bereavement, while often simultaneously feeling anxious about the prognosis for a surviving baby.

Parents generally appreciate it when staff recognise that their surviving baby is a twin. Parents usually welcome the opportunity to discuss the loss of the twin who died. Parents really value the empathy they receive from staff when one of their twins dies. Offer memory making. Parents find comfort in mementoes of both their twins. Parents can find the discharge from hospital of their surviving twin difficult. The neonatal team can provide Butterfly stickers that can be placed on or next to the cot when a baby has died, to alert staff that the baby is a survivor of a multiple pregnancy. These are available on TMBU and SCBU on request.

# Section G - Legal Entitlements

Parents who have suffered a stillbirth above 24 weeks or a neonatal death at any gestation are entitled to their full maternity/paternity rights, including maternity leave and pay.

Parents who have suffered a miscarriage before 24 weeks are only entitled to maternity/paternity rights if there baby was born with signs of life and was registered as a live birth and subsequent death.

Sick leave related to a miscarriage before 24 weeks is protected in the same way as sick leave for a pregnancy related illness, so women are not limited in how much they can take and it must be recorded separately from other sick leave.

See the leaflet "Your entitlements following the loss of your baby" for more information from my pregnancy matters. This can be found in both bereavement rooms in hard copy, and is in the SANDS packs.

# Section H - Taking baby home

Some parents find it comforting to have time with their baby outside of the clinical setting. This may also be an opportunity for siblings and other relatives to see the baby and create memories. Please use the form "Taking baby home" (Appendix 8) and ensure parents are advised to keep baby cool. Parents should be loaned a cold cot and shown how to use it – there are two at each site. Please contact the pregnancy loss midwives if you need advice.

There is no legal reason why the parents may not take the baby home unless the case has been referred to the coroner.

Parents who do not wish to take their baby home should be offered the opportunity to stay in hospital for long enough to spend time with their baby. Parents should not feel rushed to leave.

# Section I - Funeral arrangements

According to the coroner products of conception below 23 weeks plus 6 days which at no stage have shown signs of independent viability are the property of the parents and if parents so wish they can remove them from the hospital. If parents wish to remove the baby /products of conception then a copy of the letter (Appendix J) stating that they have taken the baby can be signed before they leave the hospital.

By law, all babies born at or after 24 weeks gestation must be formally buried or cremated.

**Private Funerals**

Parents can arrange the funeral themselves and this should be supported. Most funeral directors do not charge for babies and children, however parents should be advised to check this when they make contact. A list of funeral directors for each site can be found in Appendix 7.

A list of local funeral directors should be given to parents with their SANDS information pack. These are available at both sites, and are found in all folders regardless of gestation.

**Parents should be aware that if they are having a post-mortem, the funeral can take place when the baby is returned to the mortuary from St Thomas's. This is usually no longer than 10 days, but may be longer in some cases such as when an inquest is indicated.**

Funeral directors will not usually charge for a basic funeral for a baby (of any gestation or age). Parents should be encouraged to contact a funeral director as soon as they are ready, as they are best placed to assist them with the process.

Parents have 30 days to instruct a funeral director, after which time the hospital will arrange cremation. It is important that parents are aware of this. The pregnancy loss midwives are able to help them with this.

**Hospital Funerals**

The trust will provide a funeral for parents if they choose. These are cremations; burials cannot be arranged by the trust.

Currently at our hospitals there is no opportunity for parents to be involved in hospital funerals. These are communal services which are not publically attended. Current arrangements for ashes are as follows:

PRH – Crematorium will provide ashes for babies cremated above 24 weeks gestation if parents would like them. The bereavement office will assist with these arrangements

RSCH – No ashes are made available regardless of gestation if the hospital is arranging the cremation. If parents would like ashes they should be encouraged to use a funeral director. They will not be under any obligation to arrange or attend a service if they do not wish to.

Local information for crematoriums can be found here:

http://www.brighton-hove.gov.uk/content/community-and-life-events/deaths-funerals-and-cemeteries/childrens-memorial-garden-0

http://www.brighton-hove.gov.uk/content/community-and-life-events/deaths-funerals-and-cemeteries/woodvale-crematorium

# Section J - Bereavement Support for Parents

BSUH has responsibility to provide sensitive support at the time of death and immediately following, as well as clear and accurate information to relatives and close friends.

In the maternity wards parents can be offered further support from the Chaplain by direct referrals from the midwives or doctors 24/7 via switchboard. We can also offer parents referral by the midwives/doctors to local support groups.

Parents need to be advised that bereavement support may also fall to voluntary and religious organisations and staff in Primary health care, See appendix 3 for a comprehensive list of leaflets & support groups.

There is currently no bereavement counselling provided by BSUH for pregnancy loss. The pregnancy loss midwives are able to assist with signposting to local charities for counselling and/or group support.

# Section K - Care of Family Members

Fathers grieve too. Most fathers value the opportunity to be with the baby after death and the chance to receive mementoes and say “goodbye”. The natural tendency for staff to concentrate attention on the bereaved mother often leaves fathers feeling somewhat neglected. They are expected and to take on the practical role of decision-making and informing relatives and friends. Fathers may welcome that responsibility but they also need the same concern and sympathy afforded to their partners.

In most families where there are other children, parents will have started to involve them in the pregnancy. When the baby dies the parents may be unable to think about the effect on the other children or how they might best help and support them. Children can mourn

unseen if they do not have an adult to turn to and are not involved in the rites and rituals of death. Children are aware of death from a very early age although their understanding varies according to their personal development. By around the age of 7 most children have a fairly good grasp of what death entails. Younger children are not so logical in their thinking. They find it hard to understand that all functions and sensations cease when a person dies. Parents and staff should be prepared when a young child says something that indicates they do not fully appreciate what has happened, or the whereabouts of the baby. Young children commonly feel guilty about the death of a sibling and the parents need to discuss this with them.

Grandparents may feel distressed at the distress of their own children as well as their own sadness at the loss of a new baby in the family. Leaflets are available in the SANDS packs, and as separate booklets which are available in both Hummingbird rooms.

# **Section L -** Support for Staff

Professionals involved in caring and supporting bereaved families are likely to need support themselves. They may find it difficult to manage their personal reactions at the same time as performing a professional role – particularly if the event brings up emotions to do with their own experience of loss.

All staff involved with caring for a woman with pregnancy loss should be offered the opportunity for a 'debrief' or After Action Review (AAR) may need to be considered in some situations. Other colleagues, Supervisors of Midwives, Chaplains or the Occupational Health staff may also be approached to allow opportunities to talk over the events.

The pregnancy loss midwives are available to support staff with any support or training needs they may have on a one to one or group basis. Please contact them by email to arrange a time if you feel you would benefit from this.

Some further resources for support for professionals can be found in in Appendix 4.

# **Section M –** Datix

Ensure a Datix is completed (and document this number in the notes) to ensure the case is reviewed in a multi-professional meeting using a standardized approach.

## References

SANDS (2016) Pregnancy Loss and the Death of a Baby. Guidelines for Professionals SANDS: London, 4th Edition

Late Intrauterine Fetal Death and Stillbirth (Green-top Guideline No. 55) 2010
Thomas.J (1993) Supporting Parents When Their Baby Dies The Child Bereavement Trust: Buckinghamshire

Regan L (2001) Miscarriage: What every Woman needs to know

Lothrop.H (1999) Help, Comfort and Hope after Losing Your Baby in Pregnancy or the First Year of Life. Element Books Ltd: Dorset.

RCOG 2011 The Care of Women Requesting Induced Abortion Evidence-based Clinical Guideline Number 7. RCOG Press: London.

RCOG 2004 Good Practice No 4: Registration of Stillbirths and certification for pregnancy loss before 24 weeks of gestation. RCOG Press: London

RCOG 2005 Good Practice No 4: Registration of Stillbirths and Certification for Pregnancy Loss before 24 Weeks of Gestation. RCOG Press: London.

NHS England 2005, Saving Babies' Lives - Care Bundle for reducing stillbirth and early neonatal death

Embleton N (2016), Bereavement from a twin pregnancy - Guidelines for health professionals, Newcastle

**Appendix 1- Pregnancy Loss Team Contact Details**

# Pregnancy Loss Team Contact Details

## Lead Consultants

Jo Sinclair- jo.sinclair@bsuh.nhs.uk

David Utting- david.utting@bsuh.nhs.uk

Secretary to both: Sam Flint Samantha.flint@bsuh.nhs.uk

## Pregnancy Loss Midwives

Hayley Stevenson- Pregnancy loss lead midwife

Tel: 07825 967943

Email: hayley.stevenson@bsuh.nhs.uk

Shelley Trigwell- Pregnancy loss support midwife

Tel: 07387 257856

Email: shelley.trigwell@bsuh.nhs.uk

## Mortuary

**RSCH.**

Tel: 01273 696955 ext 4144

RSCH.mortuary@bsuh.nhs.uk

Morticians

Darren Ponsford: Darren.ponsford@bsuh.nhs.uk

Mark Ayres: Mark.ayres@bsuh.nhs.uk

**PRH**

Tel: 01444 441881 ext 8449

Mortician

Michael Brown- Michael.brown@bsuh.nhs.uk

Bereavement officer

Sarah Gunaratne- Sarah.gunaratne@bsuh.nhs.uk

Tel:01444 441881 ext 8101

## Appendix 2- Chaplaincy & Spiritual Care

CHAPLAINCY CONTACTS

**A chaplain is on-call 24/7**

**FOR URGENT MATTERS**

**CONTACT THE SWITCHBOARD FOR THE DUTY CHAPLAIN**

**OR**

**LEAVE A MESSAGE: RSCH / RACH ext. 4122; PRH ext. 8232**

***If you require a chaplain of a specific faith, tradition, belief please consult below and phone direct.***

***If you are unable to make contact, phone the Switchboard and ask for the duty chaplain.***

| Faith/Denomination | Name | Phone Numbers |
|---|---|---|
| **Christian:** | for a denomination not listed below please contact the Duty chaplain | |
| **Church of England** | Contact the Duty Chaplain via switchboard | |
| **Roman Catholic** | Contact switchboard, and ask them to page the Roman Catholic chaplain for you.<br><br>(*For the Polish Roman Catholic* chaplain: 07789897003 & 01273 720069) | |
| **Baptist** | Dave Steell | 01273 694746 |
| **Coptic Christian Church (Egyptian, Sudanese, etc)** | Father John | 01273 736636 (church) or O7775782637 |
| **Eastern Orthodox Christian Churches** | Fr. Nicodemus (Greek);<br>Fr Ian Wallis (Russian, etc.) | 01273 675396; 07799 877299<br>01273 553230, 07792589317 |
| **Greek Orthodox** | Patre Gemanos Kourkounis | 01273746653, |
| **Methodist** | Revd Robin Selmes (Brighton)<br><br>Revd David Chapman(Haywards Heath) | 01273 503348 (home)/ 605502 (Church)<br><br>01444 413498 |
| **Pentecostal Church - ELIM** | Paul Davies | 07979334288 |
| **Salvation Army** | Majors Michael & Elizabeth Lloyd | 01273 607095 |
| **United Reform** | Revd Alex Mabbs | 01273 821512, 07715873932 |
| **AIDS, HIV Chaplaincy** | Revd Heather Leake Date | 07867 773360 |
| **Bahai** — The Bahai Centre | Mona Hajatdoost | 01273 505895 |

| | | |
|---|---|---|
| **Buddhist** | Laura Shewan | 07792981029 |
| **Brighton Buddhist Centre**<br><br>**Western Tradition** | Kalyanavati | 01273 772090<br><br>07505 889949 |
| **Theravadan Buddhist** | Rory Singer | 07739 556438 |
| **Buddhist: New Kadampa Tradition** | Bodhisattva Kadampa Centre | 01273 732917 |
| **Christian Science** | Judith Weisz | 01273 302705 |
| **Hindu** | Crawley Hindu Temple (for Brighton)<br><br>Ashwin Soni (Haywards Heath) | 01293 530105<br>07833 252551 |
| **Humanist/Secular Society** | Fleur Jacot | 01273 461404 |
| **Jehovah's Witnesses** | Max Worden<br>Philip Warnett | 01903 500511/07780 961961<br>01273 674117/07801 472984 |
| **Jewish Orthodox** | Rabbi Pesach Efune<br><br>***JEWISH CHAPLAIN FOR BSUH*** | 07885 538681 |
| **Jewish Reform** | Rabbi Andrea Zanardo | (synagogue) 01273 735343<br>emergencies 07810648666 |
| **Jewish Progressive** | Rabbi Elli Sarah | 01273 737223 / 07940797136 |
| **Mormon** | Bishop Alec Mitchell | 01273 271843/07879493608 |
| **Muslim** | Imam Idris Naweb<br>***MUSLIM CHAPLAIN FOR BSUH***<br><br>Brighton & Hove Muslim Forum | 07875 540605<br><br>01273 819806; 07958 771411 |
| **Pagan** | Lyn Baylis | 01444 811756 |
| **Quaker** | Anne Howard | 01273 241127 |
| **Sikh** | Baldev Singh Dedyal<br><br>Sukhdev Ahluwalia | 07914 390091<br><br>01273 235486 |
| **Spiritualist** | Joan Bygrave | 01273 683088 |
| **Unitarian** | **Geoff jones** | 01273 696022 |

## Buddhism

### Special considerations for Buddhists

• Access to a day room or a single room may be required to provide the peace and quiet for meditation and chanting.

• The Chapel can be used for visiting Buddhists to pray with the mother and/or the use of a side room is valued.

• Hand washing facilities will be needed prior to meditation.

• The mother may wish to sleep on the floor.

• The image of a Buddha brings comfort together with flowers and an incense stick. These must be handled respectfully.

• It is important to treat the scriptures and Spiritual Writings with respect. Do not place any books or other objects on top of them.

• Many Buddhists are vegetarians.

### Requirements following death

• When fetal or neonatal death is anticipated, the parent or a representative should contact the Buddhist monk to pray or chant a blessing.

• After the death a Buddhist monk should attend before the baby is placed in the coffin. There are no restrictions on who should handle the body and there is no objection, on religious grounds, to post-mortem examination.

• There are no time requirements for the funeral however the bodies are cremated not buried.

## Christianity

### Special considerations for Christians

• There are many branches of the Christian religion, sharing the same beliefs but with different traditions and practices.

• The Hospital Chaplain, or the parents' own Minister or Priest, can provide spiritual support.

• A Bible may be requested.

### Requirements following death

• Parents may wish prayers to be said by the Chaplain or by their own Minister or Priest.

• There are no restrictions on who should handle the body and there is unlikely to be any objection on religious grounds to a post-mortem.

### Emergency Baptism

• In the case of serious neonatal illness/prematurity, the possibility of emergency baptism should be put to Christian parents. With their consent the Chaplain, or the parent's local minister, should be informed as soon as possible. In an emergency, any lay person may be the minister for Baptism, preferably in the presence of at least one other member of staff.

## Hinduism

### Special considerations Hindus

• Hinduism is defined by what people do rather than what they really think. Consequently there is more uniformity of behaviour than belief.

• There is a preference for women to be cared for by women and to preserve modesty as far as possible.

• Personal hygiene is very important, a bowl of water should be provided when a bedpan is to be used.

• Many Hindus do not eat meat and some do not eat eggs. Most drink cows milk. Care must be taken about using plates that have previously been used for serving meat. Single use plates may be used.

### Requirements following death

• Post-mortems are accepted but are disliked, particularly in the case of children and neonates.

• All procedures at death must be consulted with individual families.

• In general the midwives or other hospital staff take care of fetal deaths. It is common to bury the fetus. It used to be the practice to bury all neonates and children up to 5 years of age but increasingly in this country parents are opting for cremation.

• The family may wrap the body on a plain sheet brought from home.

• Funeral arrangements are organised through a specialist funeral director. If additional advice is required the funeral director can usually help.

## Islam

### Special considerations for Muslims

• Great importance is placed on cleanliness. A shower is preferred to a bath. A bowl of water should always be provided when a bedpan is offered.

• Preservation of modesty may be very important and women will prefer to be cared for by female staff. A woman may request that her husband or a female companion be present during a medical examination.

• Times of prayer are dawn, noon, mid afternoon, just before sunset and before retiring for sleep. The mother needs to stand on clean ground or on a prayer mat facing Mecca (southeast in Britain). Privacy is appreciated but not essential.

• During the time of Ramadan all healthy Muslims are required to fast. Ill patients and pregnant women are exempt from this. Food should be made available before dawn and after sunset.

• Taking medication during the fast may cause problems, no undue pressure should be applied. The local Mosque will provide advice and support in this situation.

• Pork and alcohol are forbidden

### Requirements following death

• No part of the dead body should be cut out, harmed or donated. A coroner's PM is the only exception.

• If it is unavoidable for a non-Muslim health worker to handle the body they should wear gloves.

## Judaism

### Special considerations for Jews

• No particular religious observance is demanded for the stillborn or liveborn baby.

• Before stillbirth/death – no form of preparation is indicated (although the observant Jewish family will constantly invoke the help and solace of the Almighty).

• Most Jews do not eat pork or offal and many will only eat kosher food.

### Requirements following death

• Ideally only Jewish people should handle the body after death, but Jewish authorities recognise that the staff must carry out a minimum of preparation of the body. Similarly, the body should be in the presence of a Jew (the 'watcher') at all times until the burial.

• A post-mortem is not permitted, although a Coroner's post-mortem cannot be refused.

• The burial should take place as soon as possible after death, although none are performed on the Sabbath or religious festivals. Set prayers are said at the funeral. The immediate relatives often undergo a seven day period of mourning ('Shiva') as for adults.

• Jewish Branch of SANDS – 020 8954 4912

## Paganism

### Special considerations for the Pagan

• Ensure that the religion is recorded correctly, not as 'no religion', or N/A

• Most Pagans will not have any unusual needs, but during one of their festivals they may ask for privacy during visiting hours to allow them to worship with their friends.

• Because of the diverse traditions within Paganism individuals should be asked how their needs can best be met while in hospital.

• Their families may not be aware of their beliefs and most Pagans are wary of making their beliefs known. Therefore this information must be treated as confidential.

• Pagans may wish to have a small white candle or a small figure of the Goddess on their locker.

• They may be vegetarian, vegan or on raw food diets

**Requirements following death.**

• It is important that Pagans have the name and telephone number of their Spiritual advisor to attend them. The Chaplain would be inappropriate unless requested.

• Cremation or burial are acceptable.

## Rastafaranism

**Special consideration for the Rastafarian**

• Rastafarians may be reluctant to accept Western medicines, preferring to use alternative therapies. They may be reluctant to answer questions.

• Fear of contaminating the body influences the attitude to transfusion.

• Many consider legal marriage to be unnecessary and extended families may be very complex.

• Rastafarians may be unwilling to wear hospital garments that have been worn by others, disposable theatre gowns may be more acceptable.

• Visiting the sick is important and visitors often arrive in large groups.

• All forms of pig meat are forbidden. Some fish such as herring and sardines are not eaten. Only natural food that has not been canned or chemically treated is eaten. Some Rastafarians are vegetarian.

**Requirements following death**

• The family may pray at the bedside.

• There are no rites or rituals before or after death.

• Post-mortems and transplants are generally unacceptable.

• Burial is preferred, although cremation is not forbidden.

## Sikhism

**Special consideration for the Sikh**

- Women prefer to be treated by female staff
- Sikhs prefer to wash in flowing water before meals, after using the lavatory or bedpan
- Often vegetarian and may not eat eggs or fish.

**Requirements following death**

- The family may wish to say or sing prayers often using taped hymns or prayers.
- Sikhs are always cremated

## **Appendix 3-** Support options for families

**Support options available for families**

| | | |
|---|---|---|
| Brighton and Hove wellbeing Services | 01273 560288 | http://www.bics.nhs.uk/patient-information/brighton-and-hove-wellbeing-service/ |
| Brighton Women's Centre Counselling | 0300 002 0060 | http://www.womenscentre.org.uk/services/counselling/ |
| As You are Counselling | 07952 754859 | http://asyouarecentre.co.uk/ |
| MAPS- midwives and parents support | | It is a group run by midwives and parents who offer support and /or counselling to parents who have experienced a pregnancy loss. The group meet on the first Friday of the month at 7.30pm at PRH, it is informal and confidential |
| ALTERNATIVES | 01273 207010 | They are a service set up to support with pregnancy loss and offer counselling to women and their partners, MW can refer or you can access directly. http://www.alternatives-brighton.org |
| SANDS- local | 07540 388044 | http://www.brighton-eastbourne-worthing-sands.org.uk |
| Keepsakes | | http://www.neverlandcreations.co.uk/ |
| | | http://www.brighton-hove.gov.uk/content/community-and-life-events/deaths-funerals-and-cemeteries/childrens-memorial-garden-0 |
| | | http://www.brighton-hove.gov.uk/content/community-and-life-events/deaths-funerals-and-cemeteries/woodvale-crematorium |
| Miscarriage Association | 01924 200 799 | www.miscarriageassociation.org.uk<br>Provides information and support on all aspects of miscarriage and ectopic pregnancy |
| SANDS (Stillbirth and Neonatal Death Society) | 020 7436 5881 | www.uk-sands.org email: support@uk-sands.org<br>Offers support, through self-help groups and befriending, to those bereaved through pregnancy<br>loss, stillbirth and neonatal death. SANDS aims to encourage better awareness of the distress<br>and grief caused by the loss of a baby. |
| TAMBA (Twins and multiple births) | 01732 868000 | Gives encouragement and support to parents of twins, triplets or more. There is a specialist sub-group for bereaved parents of twins or more. |
| ARC (Antenatal | 020 7631 | Offers support and information to women and couples making |

| | | |
|---|---|---|
| Results and Choice) | 0285 | decisions about antenatal testing<br>and throughout the testing process. ARC also provides support and information to parents who<br>are told that their unborn baby has an abnormality to help them make informed decisions about<br>the future of the pregnancy. |
| BLISS (Baby Life Support System) | | Provides information for parents whose babies are or were in Neonatal Units. www.bliss.org.ukemail: information@bliss.org.uk |
| FSID (Foundation for Sudden Infant Death) | | FSID runs a 24 hour cot death helpline to give personal support. FSID also runs a support<br>programme for parents with their next child called CONI |
| Child Bereavement Trust | | Offers specialist training in bereavement counselling skills for all professionals. Also offers support to the professional career. |
| Tommy's Campaign | | Research charity about pregnancy and complications.<br>www.tommys.org |
| **Abigail's Footsteps** | | **A charity dedicated to stillbirth bereavement**<br>**http://www.abigailsfootsteps.co.uk/** |
| **Winston's Wish** | **Helpline: 0845 203 0405** | **www.winstonswish.org.uk**<br>**Help and support for bereaved young people up to the age of 18**<br>**Email: info@winstonswish.org.uk** |
| **4Louis** | | A charity dedicated to Stillbirth |
| **Oscars wish foundation** | | A charity dedicated to Stillbirth |

## **Appendix 4-** Support for Professionals

BSUH Occupational Health
https://nww.bsuh.nhs.uk/working-here/human-resources/occupational-health/

BSUH Health, Employee Learning and Psychotherapy services (HELP)
https://nww.bsuh.nhs.uk/working-here/human-resources/advice-support-and-wellbeing/help-health-employee-learning-and-psychotherapy-services/

RCM Bereavement Care Network
rcm.org.uk/bcn

BMA Useful links on your wellbeing
https://www.bma.org.uk/advice/work-life-support/your-wellbeing/useful-links

GMC Your health matters
http://www.gmc-uk.org/concerns/11542.asp

Online Health and Wellness Resource
http://ephysicianhealth.com/

International Stress Management Association
http://isma.org.uk/

Multimedia
https://www.youtube.com/watch?v=MQolbL6Qcq0
**A film commissioned by the charity Abigail's Footsteps about stillbirth through the eyes of a mother. Aimed at midwives and any other staff that work in a maternity ward to help them better understand good and bad practice in relation to a stillbirth or neo-natal death.**

## Appendix 5- Histopathology

Brighton and Sussex University Hospitals NHS Trust

Brighton & Sussex University Hospitals *NHS* Trust

**HISTOPATHOLOGY AND CYTOPATHOLOGY**
(Not Cervical Cytology)

Enquiries: RSCH 01273 664502
PRH 01444 441881 Ext 8226

**Lab number**

SPECIMEN(S) SENT:

A _____

B _____

C _____

D _____

E _____

F _____

NHS NUMBER _____ HOSPITAL NUMBER _____

SURNAME:

FORENAME(S) :

DOB: - - / - - / - - SEX: M / F

Consultant / GP: _____

Address: _____

_____

NHS / PP / CAT II

Copy to: _____

CLINICAL INFORMATION AND DIAGNOSIS _____

_____

_____

_____

_____

**Lab Use Only : T** **M** **P** Date Received:

YOUR NAME: Bleep: Date:

**Appendix 6- Post mortem consent**

Guy's and St Thomas' NHS
NHS Foundation Trust

# Perinatal/Paediatric Post Mortem Consent Form

Your wishes about the post mortem examination of your baby/child

## Your wishes about the post mortem examination of your baby/child

| **Mother** | **Baby/Child** |
|---|---|
| **Last name** | **Last name** |
| **First name(s)** | **First name(s)** |
| **Address** | **Date of birth** |
| | **Date of death** (if live born) |
| **Hospital no.** | **Hospital no.** |
| **NHS no.** | **NHS no.** |
| **Date of birth** | **Gender** (if known) |
| **Consultant** | **Consultant** |
| **Father/Partner with parental responsibility** | **Address** (if different from the mother's) |
| **Last name** | |
| **First name(s)** | |
| **Preferred parent to contact, tel. no.:** | |
| **Other, eg, religion, language, interpreter ……..**<br>**……..** | |

**How to fill in this form:**

- ***Please show what you agree to by writing* YES *in the relevant boxes.*** ***Write* NO *where you do not agree.***
- Record any variations, exceptions and special concerns in the Notes to the relevant section or in Section 6.
- Sign and date the form. The person taking consent will also sign and date it.

**Changing your mind**

After you sign this form, there is a short time in which you can change your mind about anything you have agreed to.

If you want to change your mind, you must contact:

[Department] **Mortuary, St Thomas' Hospital** [Tel.] **020 7188 3925**

Before [Time] …….. on [Day] ……. [Date] …….

**Please be assured that your baby/child will always be treated with care and respect.**

## Section 1: Your decisions about a post mortem examination *Select **one** of these 3 options.*

**A complete post mortem** This gives you the most information. It includes an external examination, examining the internal organs, examining small samples of tissue under a microscope, and taking x-rays (or other forms of imaging such as CT or MRI) and medical photographs. Tests may also be done for infection and other problems and the placenta may also be examined.

If you think you may have another baby in the future and are worried that the problem might occur again, a complete post mortem is the best way to try to find out.

☐ **I/We agree to a complete post mortem examination.**

**OR**

**A limited post mortem** This is likely to give less information than a complete post mortem.

A limited post mortem includes an external examination, examining the internal organs in the area(s) of the body that you agree to, examining small samples of tissue under a microscope, and taking x-rays (or other forms of imaging such as CT or MRI) and medical photographs. Tests may also be done for infection and other problems and the placenta may also be examined.

☐ **I/We agree to a limited post mortem examination.**

Please indicate what can be examined:

☐ **Abdomen** ☐ **Chest and neck** ☐ **Head** **Other …….**

**OR**

**An external post mortem** This may not give any new information.

An external post mortem includes a careful examination of the outside of the body, x-rays (or other forms of imaging) and medical photographs. The placenta may also be examined.

☐ **I/We agree to an external post mortem examination.**

## Section 2: Tissue samples *Only if you consent to a complete or limited post mortem*

With your agreement, the tissue samples taken for examination under a microscope will be kept as part of the medical record (in small wax blocks and on glass slides). This is so that they can be re-examined to try to find out more if new tests or new information become available. This could be especially useful if you think you may have another baby in the future.

☐ **I/We agree to the tissue samples being kept as part of the medical record for possible re-examination.** *If consent is **not** given, you must note below what should be done with the tissue samples. See Section 9 Item 6 for more information.*

**Notes to Sections 1 and 2 if required** ……

……

## Section 3: Genetic testing

To examine the baby's/child's chromosomes or DNA for a possible genetic disorder or condition, the pathologist takes small samples of skin, other tissue and/or samples from the placenta (afterbirth). With your agreement, this material may be kept as part of the medical record so that it can be re-examined to try to find out more if new tests or new information become available. This could be especially useful if you think you may have another baby in the future.

☐ **I/We agree to genetic testing of samples of skin, other tissue and/or the placenta.** *If samples should not be taken from any of these, please note this below.*

☐ **I/We agree to the genetic material may be kept as part of the medical record for possible re-examination.** *See Section 9 Item 6 for more information.*

**Notes to Section 3 if required** ……

……

## Section 4: Keeping tissue samples for training professionals and for research

*Section 4 covers additional separate consent that you may decide to give. It will not affect what you have already agreed to above, what is done during the post mortem, or the information you get about your baby's/child's condition, but it may be helpful for others in the future.*

With your agreement, the tissue samples may also be examined for quality assurance and audit of pathology services to ensure that high standards are maintained.

☐ **I/We agree to the tissue samples being kept and used for quality assurance and audit.**

Tissue samples, medical images and other information from the post mortem can be important for training health professionals. Identifying details are always removed when items are used for training.

☐ **I/We agree to anonymised tissue samples, images and other relevant information from the post mortem being kept and used for professional training.**

Tissue samples, medical images and other relevant information from the post mortem can also be useful in research into different conditions and to try to prevent more deaths in the future. All research must be approved by a Research Ethics Committee.

☐ **I/We agree to tissue samples, images and other relevant information from the post mortem being kept and used for ethically approved medical research.**

You can withdraw consent for any of the above at any time in the future. To do so, please contact the hospital and ask for the histopathology department (see contact details at end of form).

## Section 5: Keeping one or more organs for diagnostic purposes

**(This section is to be used if an organ is to be kept after the body has been released from the mortuary, if an organ needs to be kept for a period longer than the standard 10 days or if you wish to donate an organ for research or training).**

**In most cases, all the organs will be returned to your baby's/child's body within 10 days after the post mortem examination, before the body is released from the mortuary**. But occasionally the doctors may recommend keeping one or more organs for longer, to carry out further detailed examination to try to find out more about why your baby/child died. This might take several more days and so could affect the timing of your baby's/child's funeral. The person who discusses the post mortem with you will tell you if it is likely (*see Section 9 Item 9 for more information*).

☐ **I/We agree to further detailed examination of the organ(s) specified below:**

☐ **Any organ**

☐ **The following organ(s)** ……..

If you agree to further detailed examination, you also need to decide what should be done with the organ(s) after the examination:

☐ **I/We want the hospital to dispose of the organ(s) respectfully as required by law.**

☐ **I/We want the organ(s) returned to the funeral director we appoint for separate cremation or burial.**

☐ **I/We want to delay the funeral until the organ(s) have been returned to my/our baby's/child's body.**

Alternatively, after the further detailed examination, you may decide to donate the organ(s) for one or both of the following purposes:

☐ **I/We agree to donate the organ(s) to be used to train health professionals.**

☐ **I/We agree to donate the organ(s) to be used for ethically approved medical research.**

If you agree to donate one or more organ(s), they will be respectfully disposed of as required by the Human Tissue Authority when they are no longer needed.

If you change your mind about this donation at any time in the future, and want to withdraw your consent, please contact the hospital and ask for the histopathology department (see contact details at the end of the form).

**Notes to Section 5 if required**

……

## Section 6: Any other requests or concerns

.....

……

## Section 7: Parental consent

☐ I/We have been offered written information about post mortems.

☐ I/We understand the possible benefits of a post mortem.

☐ My/Our questions about post mortems have been answered.

**Mother's name** …… **Signature** …….

**Father's/Partner's name** …….. **Signature** …….

**Date** …….. **Time** ……

## Section 8: Consent taker's statements *To be completed and signed in front of the parents.*

☐ I have read the written information offered to the parents.

☐ I believe that the parent(s) has/have sufficient understanding of a post mortem and (if applicable) the options for what should be done with tissue and organs to give valid consent.

☐ I have recorded any variations, exceptions and special concerns.

☐ I have checked the form and made sure that there is no missing or conflicting information.

☐ I have explained the time period within which parents can withdraw or change consent, and have entered the necessary information at the beginning of this form.

**Name** …….. **Position/Grade** ……..

**Department** ……. **Contact details (Ext/Bleep)**……

**Signature** …… **Date** ……..**Time.** ……..

## Interpreter's statement (if relevant)

☐ I have interpreted the information about the post mortem for the parent(s) to the best of my ability and I believe that they understand it.

**Name** …… **Contact details** ……

**Signature** ……. **Date** ……..**Time** ……..

## Section 9: Notes for the consent taker

1. "Anyone seeking consent for hospital PM examinations should have relevant experience and a good understanding of the procedure. They should have been trained in dealing with bereavement and in the purpose and procedures of PM examinations and they should have witnessed a PM examination" (Human Tissue Authority, Code of Practice 3, 2009).
2. Written information about post mortems should be offered to all parents before you discuss the form with them.
3. If the parents have a specific request that you are not sure about, contact the pathologist **before the form is completed.**
4. Make sure that an appropriate time and date are entered in the *Changing your mind* section at the beginning of the form, and the parent(s) understand what to do if they change their minds. The post mortem should not begin unless this section is completed. **It is your responsibility to ensure that, if the parent(s) change their minds, they will be able to contact the person or department entered on this form.** If the parents do not want a copy of the form, they should still be given written information about changing their minds.
5. Write the mother's or the baby's/child's hospital number in the box at the foot of each page of the form. For a baby who was born dead at any gestation use the mother's hospital number; for a baby who was born alive use the baby's hospital number.
6. **Sections 2 and 3: Tissue samples and genetic material** If the parents do not want tissue samples or genetic material kept as part of the medical record, explain the different options for disposal (below) and note their decisions in the relevant section.

   If disposal is requested, it will usually take place only after the full post mortem report has been completed. The options are: disposal by a specialist hospital contractor; release to a funeral director of the parents' choice for burial; or release to the parents themselves. For health and safety reasons, blocks and slides cannot be cremated. Genetic material is normally incinerated.

7. Send the completed form to the relevant pathology department, offer a copy to the parent(s), and put a copy into the mother's (for a stillbirth or miscarriage) or the baby's/child's medical record.
8. Record in the clinical notes that a discussion about the post mortem examination has taken place, the outcome, and any additional important information.
9. **Possible further examination of one or more organs** Very rarely, it may be recommended that an organ is kept for more detailed examination after the baby/child is released from the mortuary (**e.g. for complex brain malformations and complex cardiac malformations, or for research purposes).** In this case, Section 5 *Keeping one or more organs for diagnostic purposes* should be completed.
   - **If you already know that this is recommended,** discuss it with the parents and also explain how it might affect funeral arrangements. If they consent, Section 5 should be completed.
   - **If the pathologist recommends further examination after the post mortem has begun,** they will contact you or the unit. The parents should then be contacted as soon as possible to discuss their wishes and to explain how keeping the organ might affect funeral arrangements. If they consent, Section 5 should be completed.

# Useful Contacts

**St Thomas' Hospital**

Mortuary Dept – Ext 83928

Bereavement Centre – Ext 83182

Pathology Dept – Ext 82947

Perinatal Pathologists Ext 82918

82917

82954

**Guy's Hospital**

Mortuary Dept – Ext 83930

Bereavement Centre – Ext 83218

Lead Health Professionals for Consent Training – Ruby Stewart & Zoe Rutherford x 83928

## Appendix 7- Funeral Directors

Find below a list of funeral directors, once chosen call the number and they will assist you in all necessary arrangements.

## Brighton area

| | | |
|---|---|---|
| Arka | 39 Surrey Street | 01273 766620 |
| Attree & Kent | 2 Hollingbury Place | 01273 542454 |
| Co-op | 133 London Road | 01273 607276 |
| Co-op | 44 Warren Road, Woodingdean | 01273 693994 |
| Christopher Stringer | 67 High Street, Rottingdean | 01273 306000 |
| Derriman & Haynes | 56 Ladies Mile Road | 01273 540168 |
| Denyers | 18 Lewes Road | 01273 681718 |
| Grosvenors | 110 Lewes Road | 01273 671958 |
| Newmans | 3 Trafalgar Street | 01273 681822 |
| Skinners | 145 Lewes Road | 01273 607446 |
| Wagstaffs | 29 College Place | 01273 603013 |
| Wagstaffs | 7a Longridge Avenue, Saltdean | 01273 303065 |

| | | |
|---|---|---|
| Attree & Kent | 108 Church Road | 01273 821985 |
| Bungards | 90 Sackville Road | 01273 820018 |
| Cornfords | 100 Blatchington Road | 01273 737005 |
| Cornfords | 8 Queens Parade | 01273 726766 |
| Dengates | 4 Montefiore Road | 01273 204410 |
| Hanningtons | 89 Old Shoreham Road | 01273 778733 |
| Mother & Daughter- Funeral Directors. Teresa Baker & Melissa Tanner | 20 Blatchington Road. Hove BN33YN | 01273 734242 |

## Hove Area

| | | |
|---|---|---|
| Coopers | 42 High Street | 01273 475557 |
| Lewes Funeral Care | 48a Malling Street | 01273 480270 |
| Richard Green | 28 Western Road | 01273 488121 |

## Lewes

## Newhaven / Peacehaven

| | | |
|---|---|---|
| Bennetts | 13 Bridge Street | 01273 611004 |

| | | |
|---|---|---|
| Co-Operative | 41 High Street, Newhaven | 01273 515242 |
| Wagstaffs | 227 South Coast Road | 01273 582188 |

## Portslade

| | | |
|---|---|---|
| Bakers | 60 Church Road | 01273 418464 |
| Philip Evans | 172 Old Shoreham Road, Southwick | 08453738574 |
| Simon Jeffries | Boundry Road, Portslade | 01273 411622 |

## Jewish Faith

| | | |
|---|---|---|
| Martin Gross | | 07801 599 771 |

## Funeral Directors MidSussex

| | | |
|---|---|---|
| RA Brooks and Son | 35 Wivelsfield Road, Haywards Heath RH16 4EN | 01444 454391 |
| P and S Gallagher | Fraser House 20 Sussex Road , Haywards Heath West Sussex RH16 4EA | 01444 451166 |
| Co-Operative | 6-8 South Road, Haywards Heath, RH16 4LA | 01444 448921 |
| Masters and Son | Masters House, Lewes Road Lindfield, West Sussex RH16 2LE | 01444 482107 |
| WM Collins and Son | 43 Station Road, Burgess Hill, RH15 9DE | 01444 849563 |
| Bowley Funeral Service | 30 Keymer Road, Hassocks, BN6 8AN | 01273 841711 |
| Ballard and Shortall | 12 Hartfield Road, Forest Row, RH18 5DN | 01342 822120 |

The following funeral undertakers do not charge or services to bereaved parents, I have included their telephone numbers to help give information to parents

Western Road cemetery in Hayward's Heath do not charge for graves

Cuckfield Cemetery charge £12

Walstead / Lindfield charge £25

Please inform parents that although the above do not charge for services- such as coffins or cars, if parents want extras such as head stones or extra limousines these services will incur charges.

## Appendix 8- Taking baby home

Brighton and Sussex University Hospitals NHS Trust

**Form for parents who take their baby's body home**

**TO WHOM IT MAY CONCERN**

This is to confirm that (name(s) of parent(s))

_____

of (address)_____

_____

Have taken their baby's body from (name and address of hospital)

_____

_____ Date _____

I / We, the parent(s), hereby take full responsibility for our baby whilst they are in our care. We will (tick as appropriate):

☐ return our baby to the hospital on (date)_____

☐ make our own funeral arrangements.

Parent(s) Name(s) (please print):

**Name of staff member** (please print) _____

**Position** (please print) _____

**In case of need or concern please contact:**

Staff member's name _____ Job Title_____

Department direct line _____ Signature_____

24-hour phone contact for support +44 1273 694373

## Appendix 9- Taking products home

The Royal Sussex County Hospital
Eastern Road
Brighton BN2 5BE
Tel: 01273 696955

Date

Dear

We are sorry about your recent pregnancy loss. We understand you have asked if you may take the products home to dispose of them yourself.

We would like to advise you of the possible risk of infection from the contents of the container and, for this reason, we advise you not to open the container. Please be advised of the following guidelines in regard to disposal:

- Advice on home burials and on alternative funeral practices that can minimise environmental harm, can be obtained from a number of sources, including the Natural Death Centre at www.naturaldeath.org.uk.
- People who want information on home burials must consult with your local council's Environmental Health Department and the Environment Agency who will be able to provide advice.

If you change your mind, we will take back the container but the seal must be intact and not broken.

The Trust agrees to you taking the container and its contents away from the hospital on your discharge home. It does this on the basis that you agree:

1. To accept responsibility for the safe and appropriate storage and disposal of the container and its contents, as soon as the Trust has passed them to you.
2. You will indemnify the Trust against any claims for loss, injury or damage relating to the container and its contents.

Please sign and date both copies of this letter to confirm your agreement.

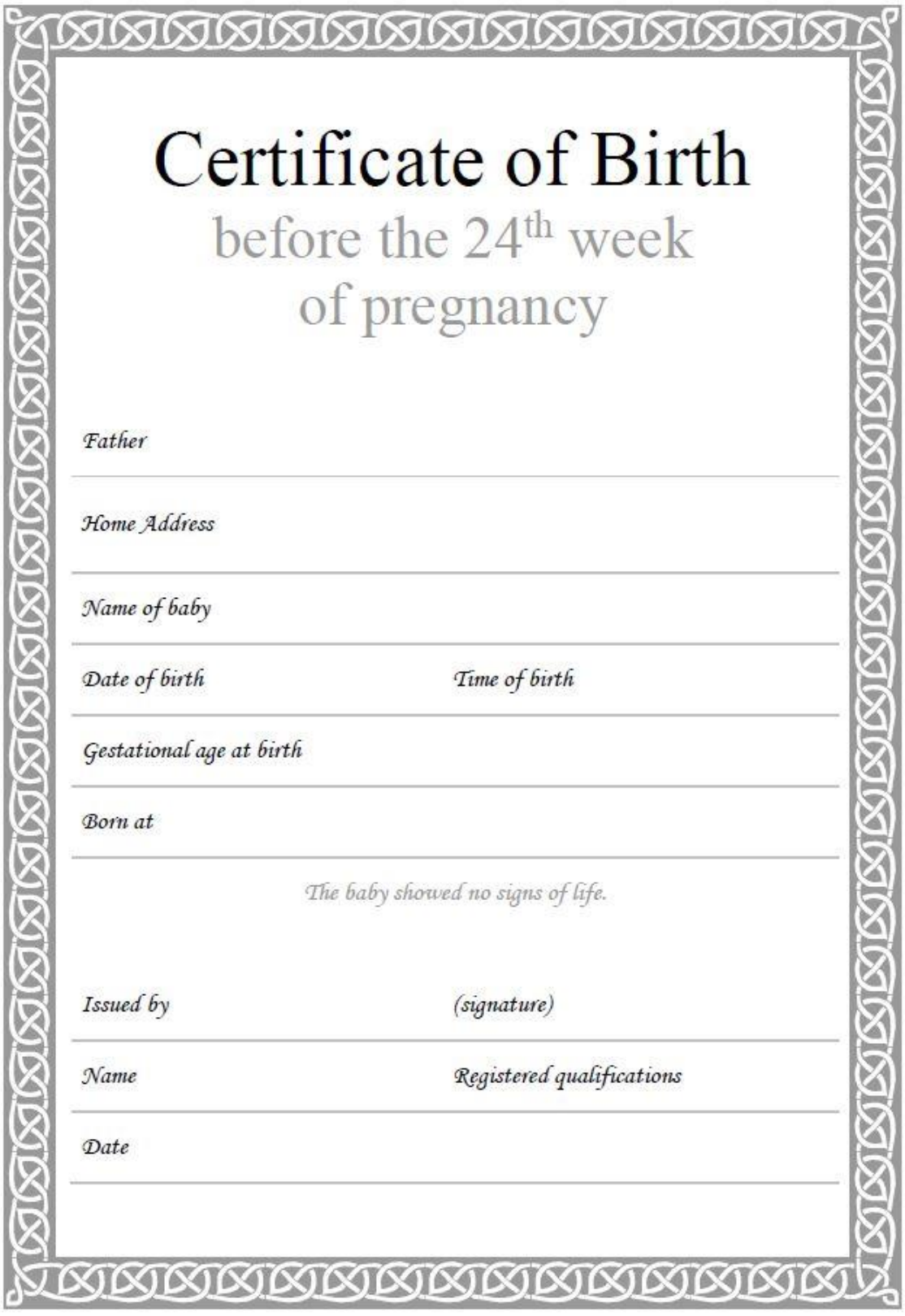
Signed (patient) …… Date …….

Member of Staff…… (Print name)

Position……

## Appendix 10-Certificate of birth

Original can be found on SANDS website or bereavement drive



# Certificate of Birth

## before the 24th week of pregnancy

*Father*

*Home Address*

*Name of baby*

*Date of birth* *Time of birth*

*Gestational age at birth*

*Born at*

*The baby showed no signs of life.*

*Issued by* *(signature)*

*Name* *Registered qualifications*

*Date*

## Appendix 11- London perinatal request

Guy's and St Thomas' NHS Foundation Trust

| | |
|---|---|
| **LONDON PERINATAL PATHOLOGY NETWORK** | |
| **PERINATAL POST MORTEM REQUEST FORM** | |
| **THIS FORM *MUST* BE SENT WITH THE BABY AND PLACENTA, ACCOMPANIED BY THE MOTHER'S SIGNED CONSENT (& NEONATAL NOTES IF APPROPRIATE)** | |
| Please fill in all details below and enclose copies of reports of any antenatal ultrasound scans. | |
| Name of Obstetrician | |
| Referring Hospital | Ward |
| Mother's case number<br>*(Use Mother's full addressograph label if required)* | Mother's DOB |
| Mother's name | Mother's ethnicity |
| Mother's address | |
| Post code | |
| Attending midwife (+ extension) | |
| Attending doctor (+ bleep number) | |
| Consultant | |
| Father's name (if known) | Consanguinity: yes/no |
| Father's ethnicity (if known) | Congenital anomalies in the family: |
| Father's age (if known) | |
| DEATH CLASSIFIED AS: (please ring) | |

| | |
|---|---|
| Fresh miscarriage | Stillbirth (> 24 weeks gestation) & death *before* labour |
| Missed miscarriage | Stillbirth (>24 weeks gestation) & death *during* labour |
| TOP for fetal malformation | TOP – other abnormality e.g. anhydramnios, Twin to Twin Transfusions (*Not* just IUD) |
| Neonatal death / death in infancy | |

**MOTHER'S MEDICAL DETAILS**

Past Obstetric history: Gravida …… Parity (prior to this delivery) ……..

Previous deliveries:

Year: Gestation: Weight: Mode of delivery: Sex:

Outcome:

Medical, drug and family history

**ANTENATAL DETAILS – RECENT PREGNANCY**

LMP …… EDD BY DATES ……. EDD BY USS …….

Gestation AT DELIVERY (or at fetocide)

CHECKLIST OF SPECIFIC PREGNANCY COMPLICATIONS:

| | | | |
|---|---|---|---|
| | | | Yes / No |
| Threatened miscarriage | Yes / No | Retroplacental clot | Yes / No |
| Down Syndrome screen | Yes / No | Maternal drugs | Yes / No |
| Abnormal liquor volume | Yes / No | Maternal diabetes | Yes / No |
| IUGR | Yes / No | Maternal hypertension | Yes / No |
| Antepartum Haemorrhage | Yes / No | Maternal smoking | Yes / No |
| Pyrexia/increased WCC/raised CRP | Yes / No | Maternal alcohol | Yes / No |
| HIV infections | Yes / No | Maternal Proteinuria / Oedema | Yes / No |
| Torch infections | Yes / No | Syphilis infection | |
| If "yes" specify: | | If "yes" specify: | |

| |
|---|
| ANTENATAL COURSE (including relevant findings from ultrasound scans, antenatal assessment or indication for interruption of pregnancy/induction of labour) |
| Karotyping done? NO / CVS / Amnio / FBS. Indication and result – |
| **LABOUR** |
| Onset Spontaneous / induced |
| Augmented? If so, how? |
| Membrane rupture Spontaneous / artificial Date and time: |
| Presentation Cephalic / Breech / Transverse / Complex |
| Duration 1st Stage 2nd Stage 3rd Stage |
| Delivery of baby: Spontaneous / Instrumental / Caesarean section<br>Indicate relevant complications (e.g. fetal distress, haemorrhage, meconium etc.)<br>Delivery of placenta: Spontaneous / Manual after retention / At caesarean section |
| **BABY'S DETAILS** |
| Name Hospital Number (if applicable) |
| Date of Birth Date of Death (if known) |
| Birth Weight Sex |

| |
|---|
| If baby was born dead when was fetal heart last heard?<br><br>When were fetal movements last perceived by mother?<br><br>Date and time of fetocide (if applicable) |
| If fresh stillbirth or livebirth, was resuscitation attempted? Yes / No |
| Clinical diagnoses: |

**ADDITIONAL INFORMATION FOR NEONATAL DEATHS**

**(for stillbirths, miscarriages and TOPS please go to the bottom of the page)**

Summary of clinical course after initial resuscitation:

| | | | | |
|---|---|---|---|---|
| Ventilation? | Yes / No | Type | Days | Max. pressures |
| Suspected infection? | Yes / No | Details | | |
| Antibiotic therapy? | Yes / No | Details | | |
| Brain USS | Yes / No | Details | | |
| Fits? | Yes / No | Details | | |
| Episodes of collapse? | Yes / No | Details | | |
| Pneumothoraces? | Yes / No | Details | | |
| Feeding: | Enteral/TPN | | | |

Other information:

| |
|---|
| |
| Special points to be noted / answered at PM: |
| Date of post natal appointment: |

## Appendix 12- Perinatal referral form

Guy's and St Thomas' NHS
NHS Foundation Trust

### Perinatal / Paediatric Post Mortem Referral Form

*Please ensure you phone St Thomas' Mortuary on 020 7188 3928 to arrange the date and time of the Post Mortem after sending this form. Thankyou.*

Name of referring hospital /

Name of Baby / Mother: _____

NHS Number of Mother: _____ Mum DOB: _____

Mums address: _____

GP Surgery and GP name: _____

Age / Gestation: _____ Date of delivery: _____ Date of death: _____

Brief outline: _____

_____

_____

_____

Name of referring person: _____ Job title: _____

Contact number: _____ Email: _____

☐ Post mortem accepted by St Thomas's

☐ Date and time arranged: _____

☐ Have you rang the above number to confirm the PM has been accepted

☐ Post Mortem consent form been completed correctly and signed?

☐ Request form completed?

☐ Post Mortem Checklist completed?

☐ Notes accompanying baby - scan reports. Photocopies acceptable

☐ No samples should be sent with the baby. Any samples taken at the referring hospital must be processed in it's own laboratories

☐ Fresh placenta should be sent with baby if applicable

X-Rays to be carried out at St Thomas' Hospital Mortuary

## Appendix 13- genetic specimen form

viapath

Guy's and St Thomas' NHS
NHS Foundation Trust

### GENETICS SPECIMEN FORM

Genetics Laboratories, 5th Floor, Tower Wing, Guy's Hospital, Great Maze Pond, London, SE1 9RT
http://www.viapath.co.uk/departments-and-laboratories/genetics

MOLECULAR GENETICS: T: 020 7188 1696/2582 F: 020 71887273
CYTOGENETICS: T: 020 71881709 F: 020 71881697
BIOCHEMICAL GENETICS: T: 020 71882591 F: 020 71887275
CLINICAL GENETICS: T: 020 71881364 F: 020 71881369

**PATIENT DETAILS**

Surname:

First Name:

Previous Name:

DOB: Sex: M / F

Address:

Postcode:

Ethnic Origin:

Hospital Number:

PRU Number:

**NHS number** (mandatory):

Private Patient (please attach invoicing details) ☐

**REFERRING HOSPITAL**

Consultant:

**Full address for return of report including department:**

Signed: Date:

Name (PRINT): Tel no:

E-mail:

**G.P DETAILS**

Name:

Postcode:

**SAMPLES**

Blood in potassium EDTA
(DNA / MLPA / array CGH) ☐

Blood in lithium heparin
(Chromosome rearrangements / Biochemical Genetics) ☐

Prenatal sample (Please circle) CVS / AF / POC

Other (Please state) _____

**Date and time sample taken:**

**Please ensure specimens are dispatched to the laboratory promptly after sampling**

**TESTS REQUESTED**

NB For testing for chromosome imbalance (array CGH/chromosome analysis), please provide clinical details on the reverse of this form.

In submitting this sample, the clinician confirms that consent has been obtained:
(a) for testing and possible storage
(b) for the use of this sample and the information generated from it to be shared with members of the donor's family and their health professionals (if appropriate).
(c) we assume that consent has been obtained for sensitive disposal of any fetal remains unless otherwise stated.

**Please do NOT send the consent form**

**CLINICAL DETAILS/REASON FOR REFERRAL**

(Please include full details of patient, with pedigree if relevant)
NB For testing for chromosome imbalance (array CGH/chromosome analysis), please provide clinical details on the reverse of this form.

Has this case been discussed with the Genetics Department? If so, with whom?

Is the patient pregnant? Y / N

If YES: how many weeks gestation? _____

**All fields above are mandatory. Samples supplied with inadequate or illegible information, will be subject to delay or rejection.**

**For departmental use only**

Issued by J. May & R. Hall 25/05/2016 Page 1 of 2 MF-G-4 Version 6.3

viapath

Guy's and St Thomas' NHS
NHS Foundation Trust

## GENETICS SPECIMEN FORM

Genetics Laboratories, 5th Floor, Tower Wing, Guy's Hospital, Great Maze Pond, London, SE1 9RT
http://www.viapath.co.uk/departments-and-laboratories/genetics

MOLECULAR GENETICS: T: 020 7188 1696/2582 F: 020 71887273
CYTOGENETICS: T: 020 71881709 F: 020 71881697
BIOCHEMICAL GENETICS: T: 020 71882591 F: 020 71887275
CLINICAL GENETICS: T: 020 71881364 F: 020 71881369

NHS Number: _____

### CLINICAL INFORMATION – for chromosome imbalance testing

*Place an X in the box if statement applies to the subject.*

**1. Cognitive Development**

Typical ☐

Delay (Atypical) ☐
Mild (IQ 50-69; for adults mental age 9-12 yrs) ☐
Mod (IQ 35-49; for adults mental age 6-9 yrs) ☐
Severe (IQ 20-34; for adults mental age 3-6 years) ☐
Profound (IQ <20; for adults mental age <3 years) ☐

**2. Specific Developmental Disorder**

Speech & language ☐ Reading/spelling ☐ Arithmetic ☐ Motor skills ☐

**3. Neurodevelopmental/Behavioural Problems**

Autism Spectrum Disorder ☐ ADHD ☐
Tics ☐ Sleep ☐ Feeding ☐ Psychosis ☐ Other Behavioural Problems ☐

**4. Neurological Disorders**

Vision ☐ Hearing ☐ Abnormal tone Involuntary Movements ☐
Structural brain lesion (eg dysplasia, tumour)
Cerebral Palsy Unilateral ☐ Cerebral Palsy Bilateral ☐
Epilepsy ☐
Age of onset: <3 months ☐ 3-24 months ☐ > 24 months ☐
Seizure type documented: atonic ☐ myoclonic ☐ other ☐

**5. Growth abnormalities**

At birth: Small for gestational age (<10th centile) ☐ Large for gestational age (>90th centile) ☐
Current: Tall stature (height >95th centile) ☐ Short Stature (height < 5th centile) ☐
Macrocephaly (>95th centile) ☐ Microcephaly (<5th centile) ☐

**6. Congenital Malformations/Dysmorphism**

Heart disease (eg ASD, VSD) ☐ Renal and Urogenital malformations ☐ Brain malformations ☐
Eye malformations (eg anophthalmia, microphthalmia) ☐ Ear malformations ☐
Cleft Lip ☐ Cleft Palate ☐ Micrognathia ☐
Limb abnormalities (eg short or long bones) ☐ Digital abnormalities (eg syndactyly, polydactyly) ☐
Facial dysmorphism eg hypertelorism ☐

**7. Endocrine and metabolic conditions** ☐

**8. Cutaneous stigmata/skin lesions** ☐

**9. Hair, nail, teeth abnormalities** ☐

**10. Other Skeletal abnormalities eg scoliosis** ☐

## Appendix 14- community midwife form- PRH & RSCH

Information for Community M/W following a pregnancy loss.

**East Grinstead** **Amber** **South Downs**

| | | | | |
|---|---|---|---|---|
| Hospital number | | | Mums DOB | |
| Name: | | | Parity: | |
| Address: | | | Gestation: | |
| | | | SVD | Em. LSCS |
| | | | Assisted | El. LSCS |
| Tel number: | | | Baby: | Male/Female |
| GP: | | | Name: | |
| CMW: | | | Date of birth: | |
| SW: | | | Time: | |
| Targeted | Yes | No | Weight: | |
| Medical/Obstetric | Mental Health | Multiple birth | Post Mortem | Yes/No |
| Domestic abuse | Teen | | Funeral: | |
| Parent education cancelled: | | Yes/No | | |
| Date of discharge: | | | Form completed by: | |
| History: | | | | |

Postnatal visits to be completed by CMW office:

| Date | Day | Comment | Given out by | Midwife |
|---|---|---|---|---|
| | | | | |
| | | | | |
| | | | | |

Information for Community M/W following a pregnancy loss.

**East** **West** **North**

| | | | | |
|---|---|---|---|---|
| Hospital number | | | Mums DOB | |
| Name: | | | Parity: | |
| Address: | | | Gestation: | |
| | | | SVD | Em. LSCS |
| | | | Assisted | El. LSCS |
| Tel number: | | | Baby: | Male/Female |
| GP: | | | Name: | |
| CMW: | | | Date of birth: | |
| SW: | | | Time: | |
| Targeted | Yes | No | Weight: | |
| Medical/Obstetric | Mental Health | Multiple birth | Post Mortem | Yes/No |
| Domestic abuse | Teen | | Funeral: | |
| Parent education cancelled: | | Yes/No | | |
| Date of discharge: | | | Form completed by: | |
| History: | | | | |

Postnatal visits to be completed by CMW office:

| Date | Day | Comment | Given out by | Midwife |
|---|---|---|---|---|
| | | | | |
| | | | | |
| | | | | |

**Appendix 15- Pregnancy loss information for secretaries**

# Pregnancy Loss Information - PRH

| | |
|---|---|
| Mothers name: | |
| DOB: | Hospital No: |
| Telephone: | Address: |
| Consultant: | |
| | |

## Type of loss

Please circle and indicate paper work completed.

| **Termination of Pregnancy?** | **Y/N** | **Abortion Form A Completed** | **Y/N** |
|---|---|---|---|

| **12- 23+6 MISCARRIAGE** | | **STILLBIRTH** | | **BORN WITH SIGNS OF LIFE** | |
|---|---|---|---|---|---|
| P2 been completed | Y/N | Woodvale form 9 completed | Y/N | Woodvale form 4 completed | Y/N |
| Sent to relevant places | Y/N | Stillbirth certificate given to parents | Y/N | Coroner been informed and death certificate given to parents | Y/N |

| **Postmortem** | |
|---|---|
| YES | NO |
| If yes, has the form been faxed to St Thomas's | Y/N |
| **Funeral arrangements** | |
| Own | Hospital |
| Form completed by: | |

Please fully complete this form:

- Original to bereavement office (Via internal mail)
- Copy to be filed in notes.

**Appendix 16- Coding form RSCH**

# Please send these notes to coding.

# Once coded please track notes to:

# Sam Flint

# Level 11 Obstetric secretary as urgent-

# Thank you.

| | | |
|---|---|---|
| **Consultant** | | |
| **Date of Delivery** | | |
| **PM** | **Yes** | **No** |

| **Follow up** | |
|---|---|
| **Results back** | |
| **Appointment Date** | |

**Appendix 16- Coding form PRH**

# Please send to coding.

## Once coded please send notes to:

## Gynae secretaries office PRH.

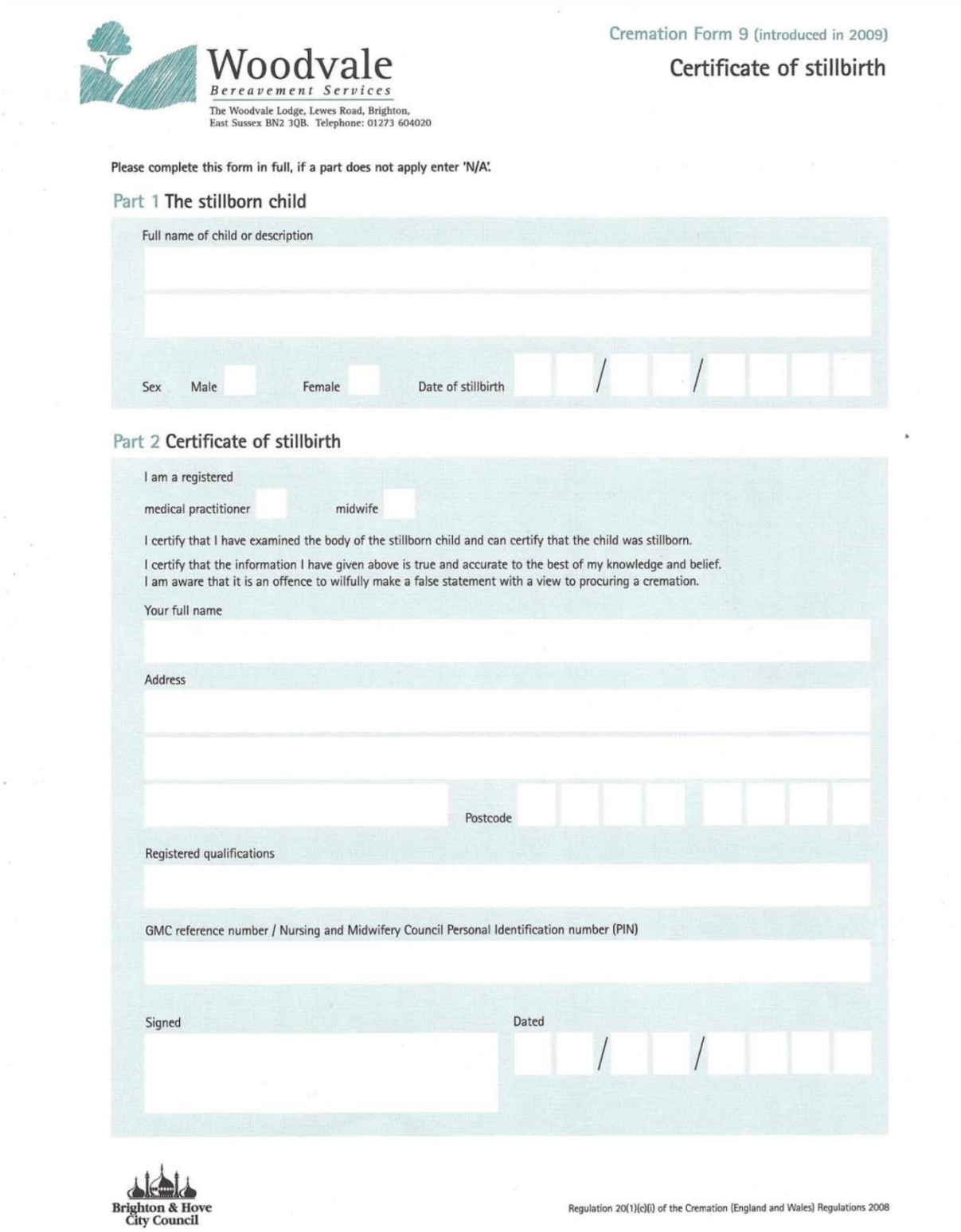
## FAO- Bereavement midwife

# Thank you.

| For bereavement MW use | | |
|---|---|---|
| Consultant | | |
| Date of Delivery | | |
| PM | Yes | No |

| Follow up | |
|---|---|
| Results back | |
| Appointment Date | |

## Appendix 17- Cremation form 9



Woodvale
Bereavement Services
The Woodvale Lodge, Lewes Road, Brighton,
East Sussex BN2 3QB. Telephone: 01273 604020

Cremation Form 9 (introduced in 2009)

Certificate of stillbirth

Please complete this form in full, if a part does not apply enter 'N/A'.

Part 1 The stillborn child

Full name of child or description

Sex Male Female Date of stillbirth / /

Part 2 Certificate of stillbirth

I am a registered

medical practitioner midwife

I certify that I have examined the body of the stillborn child and can certify that the child was stillborn.

I certify that the information I have given above is true and accurate to the best of my knowledge and belief.
I am aware that it is an offence to wilfully make a false statement with a view to procuring a cremation.

Your full name

Address

Postcode

Registered qualifications

GMC reference number / Nursing and Midwifery Council Personal Identification number (PIN)

Signed

Dated / /

Brighton & Hove City Council

Regulation 20(1)(c)(i) of the Cremation (England and Wales) Regulations 2008

## Appendix 18 – Referring neonatal Deaths to the Coroner

# REPORT OF DEATH BY DOCTOR TO THE SENIOR CORONER FOR WEST SUSSEX

Please **type** this form -the coroner's officers will copy and paste **your** text onto another document.

Complete every space –Omissions cause delay for bereaved relatives.

Then **email** to the relevant coroner's officer at –

Horsham Office– west.sussex.coroner@sussex.pnn.police.uk
(Horsham, Crawley, Mid Sussex, Gatwick)
Worthing Office – WS.Coroners.Wor@sussex.pnn.police.uk
(Worthing, Chichester, Arun, Bognor Regis, Littlehampton, Midhurst, Petworth)
(Your own hospital bereavement office may be able to do that.)

As soon as a coroner's officer is able, s/he will telephone the bereavement office / Surgery. If there is sufficient information on the report of death form then, by the time of that call, the Senior Coroner will usually have decided whether a post mortem examination is to take place. However, further discussion with the reporting doctor and/or general practitioner may be necessary before that decision can be made.

The reporting doctor may not issue an MCCD to a family until the coroner's officer has indicated the Senior Coroner's agreement. Relatives should not be promised any time frame for this, as court commitments take priority.

When a medical cause of death is agreed by the Senior Coroner, the doctor signing the MCCD must indicate on it that the coroner has been informed, and must record the cause **exactly** as finally agreed with the coroner's officer, with no abbreviations. Otherwise, the bereaved family will be unable to register.

**Reports of death are dealt with during office hours only.**
**Monday to Friday, 8am to 4pm**

**For out of hours queries re organ donation or homicides,**
**Call Sussex Police on 101, and a coroner's officer will call you back.**

**Reason for referral to the Senior Coroner**

**Those cases marked with an asterisk must also be referred to the police.*

| | |
|---|---|
| ☐ | the cause of death is unknown |
| ☐ | the deceased has not been seen by a Doctor within the last 14 days |
| ☐ | * death may have been caused or contributed to by assault or violence |
| ☐ | * death may have been caused or contributed to by non-violent trauma, whenever it occurred (e.g. a fall at home or a road traffic collision) |
| ☐ | * death may have been caused or contributed to by poisoning, whether intentional or accidental, but not food poisoning |
| ☐ | * death may have been caused or contributed to by the deceased's actions e.g. by drug use, self harm or self neglect |
| ☐ | * death may have been caused or contributed to by neglect |
| ☐ | * death occurred whilst in custody – police or prison or compulsory detention under section of the Mental Health Act |
| ☐ | * death occurred shortly after police contact or may have been caused or contributed to by police action or inaction |
| ☐ | death may have been caused or contributed to by the deceased's employment |
| ☐ | death occurred during or immediately after an operation or within 24 hours of an anaesthetic or occurred within 24 hours of admission to hospital |
| ☐ | death may have been caused or contributed to by a medical procedure or treatment, whether invasive or not |
| ☐ | death may have been caused or contributed to by a lack of treatment |
| ☐ | there are other concerning features of the death – please say what |

**Details of Deceased**

| | |
|---|---|
| Name of hospital / Surgery: | Princess Royal Hospital Haywards Heath |

| | | | |
|---|---|---|---|
| Name of deceased: | | | |
| Date of birth: | | | |
| Address: | | | |
| Place of death if different from above | | | |
| Gender: | | | |
| Hospital no: | | CAD no: | |

| | | | |
|---|---|---|---|
| Date of death: | | Time: | |
| Name of doctor recognising life extinct: | | | |
| Grade and specialty: | | | |
| Name of reporting doctor:<br>(who must have treated the deceased) | | | |
| Grade and specialty: | | | |
| Reporting doctor's bleep number: | | | |
| Name of treating consultant: | | | |
| Date of admission to hospital: | | | |

| | |
|---|---|
| GP name: | |
| GP telephone: | |
| GP surgery address: | |

| | |
|---|---|
| Name of next of kin: | |
| Relationship to deceased: | |
| Telephone number(s) of next of kin: | |
| Does next of kin know of death? | |

**Chronology of presenting complaint, treatment and death.**

**This must include past medical history; medication; reason for admission and incident address (e.g. "unwitnessed, but remembers tripping on rug and falling downstairs at home" or "passer-by described to ambulance team witnessing epileptic seizure on platform at Seven Sisters Underground");any family concerns regarding care; and location where deceased currently lies.**

**If reporting doctor is able to issue MCCD, proposed cause of death:**

1a
1b
1c

2

Remember, the medical cause of death ultimately accepted by the Senior Coroner must be reproduced on the MCCD, with no abbreviations, **exactly as agreed with the coroner's officer**. Otherwise, the bereaved family will be unable to register.

## Appendix 19- Pregnancy Loss – Giving Birth

The way that you give birth to your baby will depend on your individual circumstances. You will be able to talk about your options with your midwife and a senior doctor.

It is usually recommended that your labour is induced, and that you aim to have a vaginal birth. This may come as a shock for you. A normal birth is usually safer for you, allows you to have a faster recovery and avoids added risks in future pregnancies if you were to have a caesarean section.

We assure you that you will have dedicated one to one care from a midwife throughout, and you will have access to effective pain relief of your choice. Your midwife and doctor will talk you through this at every stage.

**Induction of labour**

If you agree to have your labour induced, you will usually be offered a tablet to take by mouth in the first instance. This prepares your body to go into labour and takes some time to work. We will usually suggest that you go home after taking this, and return to hospital the next day or the day after. It is important that you call the labour ward if:

- You feel unwell or worried
- You think your waters may have broken, if they haven't already
- You think that your labour has begun

During this time at home, many women feel very frightened about what is to come. Please don't hesitate to call the labour ward at any time, for any reason. If you feel that you would prefer to stay as an in-patient, and that going home is too distressing, please speak to your midwife as we can usually help you.

When you return to the hospital, we will usually use a vaginal pessary to continue your induction. After this you will be given a tablet form of the same drug at regular intervals until your labour is established.

Your midwife will available to support you and your partner or birth companion at all times. You are not alone.

**If you choose not to be induced** If you are healthy, and would prefer to wait for labour to begin naturally, we will support you with this. Due to the increased risk of you becoming unwell, we recommend that you have regular blood tests and a check-up at the hospital (usually twice a week). If there is a long wait before labour commences, your baby's condition may deteriorate in your womb. This may make it more difficult for a post-mortem to provide useful information, if you would like to have one.

Remember, your midwife, doctor, or a member of the pregnancy loss team will be able to help you make these important decisions.

## Appendix 20- P2 form

**(Do not print this form)**

*Top (blue) copy with baby, 2nd copy (white) to bereavement office, 3rd (yellow) to patient, 4th copy (pink) copy to notes*

Brighton and Sussex University Hospitals NHS Trust

**Pregnancy Losses 12 – 23 weeks gestation** (according to size by scan)
**P2 Form**

| | |
|---|---|
| Patient's tel. no.: | Trust ID No: |
| | Mothers name: |
| Consultant: | Date of birth: |
| | Address: |
| Father's name: | |

***Current & previous pregnancies***

| | |
|---|---|
| Parity: | Tissue type: |
| LMP/Gestation: | Ward source: |
| Clinical details: | Date of pregnancy loss: |

***Post mortem verbally agreed? (Ensure additional consent booklet is completed by staff and parents)***

☐ Yes ☐ No (send direct to mortuary) ☐ No (home with parents)

Where post mortem is not desired, any tissue from you or your baby, including any from theatre procedures, may be sent to the histopathology laboratory for examination which may include examination under a microscope.

We encourage parents to make their own private funeral arrangements for their baby. It may be too soon to decide now but, if you do decide to make your own arrangements, you must contact the Bereavement Office (PRH 01444 441881 Ext: 8101 or RSCH 01273 696955 Ext: 4611) **within 30 days** of the date on this form, otherwise the hospital will arrange a simple cremation but there will be no service for you to attend nor ashes to collect.

**Confirmation by mother**: I confirm that the process above has been discussed with me and I confirm I have also received the *Your Baby – 12 to 23 weeks* leaflet.

Signed …….. Date……

**The following must be completed by the Doctor. If this form is NOT completed it will be returned to the relevant person for completion before cremation can take place**

I declare to the best of my belief that the above has been identified as a pregnancy loss of less than 24 weeks gestation, that has at no time shown any sign of life and that all the information given in this application is correct.

| | | | |
|---|---|---|---|
| Signed | …… | Date | …… |
| Print name | …… | Qualifications | …… |

*POC P2 form 12 to 23 weeks*

File in Clinical Notes

## Appendix 21 - Maternity Bereavement Audit Tool 2017

Age _____ Parity _____ Gestation _____+_____

Ethnicity: ☐ White ☐ Mixed ☐ Asian ☐ Black ☐ Other

Weight < 10th Centile: ☐ Yes ☐ No

Mode of Delivery: _____

| | | Yes | No |
|---|---|---|---|
| 2.8 | Given 24 hr contact number | | |
| 4.1 | AN appointments cancelled | | |
| 5.1 | GP/ CMW informed within 1 working day | | |
| 6.2 | Not left alone in labour | | |
| 6.4 | Analgesia discussed, i.e. PCA | | |
| 6.11 | Record decisions about seeing and holding baby | | |
| 6.13 | Offered foot prints and photo | | |
| 6.17 | Tear Drop sticker | | |
| | Offered cabergoline | | |
| | Haematology/ Microbiology tests complete | | |
| 7.5 | Offered contract with member of parents' faith | | |
| 7.6 | Post-natal Check | | |
| 7.8 | Given contact information when they leave | | |
| 8.1 | Offer to take body home | | |
| 8.3 | If they take the body home, are they given a form? | | |
| 9.1 | Offered PM | | |
| 9.3 | Written information on PM | | |
| | Accepted PM | | |
| 9.6 | Post-natal appointment within 12 weeks | | |
| 10.1 | Given information on registering stillbirth (if > 24 weeks) | | |
| 11.1 | Given information on funeral arrangements (if > 24 weeks) | | |
| 12.2 | Given details of Baby Mailing Preference Service | | |
| 12.4 | Given written information of support organisations | | |
| | Check list complete | | |
| 14.1 | Offered extra monitoring in future pregnancy | | |
| 15.1 | Was an interpreter/ signer needed? | | |
| 18.1 | Datix complete | | |

*SANDS Audit Tool for Maternity Services

Cause of IUD _____

None Identified ☐